

Critical success factors that enable individuals to die in their preferred place of death



A report based on contributions from End of Life
Care commissioners and providers of services
within seven PCTs areas

February 2012





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Foreword

Since this work was commissioned, the National End of Life Care Programme and the Department of Health's End of Life Care Policy Team have taken on joint leadership for the QIPP (Quality, Innovation, Productivity and Prevention) End of Life Care work stream. This piece of work on Critical Success Factors now forms an integral part of our overall plan to support others in responding to the EoLC QIPP agenda by identifying those factors that have made a difference and enable more people to die in their preferred place of death.

It is intended as a starting point to help those commissioning and planning their services to see what has worked in other areas. We are not suggesting that one size fits all, but the work has shown us how much can be achieved where individuals bring commitment and dedication to driving change forward. It has been especially noticeable that even with the wider changes happening across health and social care there are still many people willing and able to drive through change and find innovative ways to breach barriers.

We would like to thank all who took part and agreed to share their work and would urge you not just to read the Executive Summary but to look at the main report and the individual profiles. They in particular showcase the extent of the activity and the quality of the examples cited which in many cases could not be included in the main report.

We now intend to do further work building on the recent QIPP showcase events as well as the NICE commissioning guidance for end of life care, also recently launched, to set this work in context and support new organisations such as the NHS Commissioning Board in keeping End of Life Care high on the national agenda.

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Executive Summary

Introduction

This report was commissioned by the National End of Life Care Programme (NEoLCP), supported by the Department of Health's End of Life Care Policy Team and the national QIPP team. Support was also provided by the South West Public Health Observatory (SWPHO).

Surveys generally indicate that between 60% and 70% of people would prefer to die in their home, whilst figures show that over half of the number of people dying each year do so within an acute hospital setting.

The main aim of this work was to try to identify the factors that influenced increases in numbers of people being able to die in their preferred place of death, which can largely be assumed to be outside of acute hospital settings, but is not always. For some the hospital is their preferred place, while for others it may not be clinically viable for them to be cared for outside of the hospital environment even if they would wish to be.

The work was not undertaken as an academic review, but based on conversations and information gathered. Seven PCT areas were chosen to reflect significant proportional achievement in percentage increases in people dying outside of the acute setting according to ONS data available, and those at the higher end of the overall percentages of deaths outside the acute setting for England. Also included were those reflecting differing profiles such as prospering UK, coastal and countryside, mining and manufacturing as well as city and London suburbs.

In total over 40 people contributed to this work and a full profile for each of the PCT areas containing initiatives being undertaken, case studies and examples of new roles being introduced are contained in Appendix D of the main report. These profiles show variations in models adopted in areas such as 24/7 services, hospice at home, information systems, coordination across boundaries as well as the efforts by individuals to make a difference.

The work commenced in August 2011 and was completed and presented to the DH End of Life Care Programme Board in December 2011.

Section 1 of the main report provides more detail on the process followed.

Critical Success Factors

The factors that are considered critical are (not ranked):

- Strong commissioning and clinical leadership
- Use of nationally recognised drivers that attract payment – LES and CQUINs
- Flexible budgets and care packages
- Use of nationally recognised tools or their local equivalent – ACP, GSF, LCP, PPC, ADAs and CHC Fast Track Pathway
- Shared electronic information systems
- Clearly defined access to 24hr cover
- Development of Care Homes
- Use of facilitator roles and coordination of care across boundaries
- Training to support staff delivering EoLC



There were a number of emerging themes: often the influences are intangible and reflect a number of contributing factors; no one model fits all; community services need improving to achieve whole systems change; and the current boundary and reorganisational changes bring uncertainty and make progress difficult.

In addition, with length of stays generally in hospital reducing, the pressures on District Nursing services is growing and the expectation that they are key to delivering more end of life care to support fast track continuing care packages and other discharges has caused concern. The number of DNs is around 10,000 and training numbers are reducing. This will potentially lead to delays in discharges and impact on the provision of 24/7 services.

Overall whilst wanting to achieve all elements around the wider QIPP agenda, the focus for those who contributed was very much about raising the quality of seamless services for individuals and their families facing the end of life. The following are factors that are considered necessary to influence change. Brief extracts of the underpinning thinking and examples are given, but full details of these and other examples can be found in Section 2 of the main report and the individual area profiles in Appendix D:

Strong commissioning and clinical leadership

- It was evident that where a PCT EoLC commissioner had experience and knowledge around the whole system approach it was easier to reinvest and redesign services. As an example the Croydon PCT lead commissioner has provided for the profile a full briefing which outlines the related work undertaken in the area and the positive results of the past year
- Clinical leadership as demonstrated by a number of contributors as well as GP, LCP, GSF facilitators were given as examples of local champions

Use of nationally recognised drivers that attract payment – Local Enhancement Schemes (LES) and CQUINs

- Necessary drivers to make GPs engage
- In Croydon a LES was developed with GPs to achieve higher preferred place of care (PPC) levels and reduce acute admissions – this has resulted in 95% of the registered population being covered by practices signed up to the LES and as a result in 2010/11 300 hospitals admissions were avoided
- BANES are just introducing a LES to support GPs develop enhanced services in Care Homes with Nursing. By November over half the practices have expressed an interest and that will cover a significant number of care beds.
- BANES have also introduced CQUINs within the acute hospital which includes an indicator 'Patient dying in the place of their choice' as well as others to support EoLC schemes including training, introduction of registers and reduction in hospital deaths for over 65's.

Flexible budgets and care packages

- Flexible joint budgets across health and social care were highlighted by most as the best way to facilitate a seamless care package and avoid delays in discharges
- Care packages need to be flexible so that if the individual's circumstances change the care package can change without any major delays.



Use of nationally recognised tools or their local equivalent – ACP, GSF, LCP, PPC, ADAs and Fast Track Pathway (CHC)

- National tools, or localised versions, were utilised to some degree by all and recognised as contributing to clear protocols and understanding of processes across boundaries
- Continuing Care Packages available as part of the CHC fast track discharge processes have facilitated more people being able to move to their PPC but grey areas surround those not meeting the criteria
- Using an ACP process and its outcomes was seen as the main element to delivering preferences for the individual
- Local resource packs, such as that developed by Trinity Hospice in Blackpool, provide a range of resources and is given out to all GP practices. Positive feedback has attracted funding to expand the provision to other professionals
- Use of ADAs (GSF or local equivalent) as an audit tool to check progress and inform further improvements.

Shared electronic information systems

- Seen as vital to ensure proper coordination across services and recording the individuals preferences
- Complex to get one system to cover all sectors – many in the primary and community care sectors work very well but do not link with systems in the acute settings – this hampers patients admitted through A&E and no information is available to the hospital or the ambulance staff.

Clearly defined access to 24hr cover

- Different models exist but needs to be clear to all in their locality – single point access was raised as beneficial to the patient and carers
- Oxfordshire have introduced the Rapid Intervention Service for EoLC (RISE) which aims to assess within 4 hours of referral if before 6pm – provides support from HCAs for up to 6 days
- St Cuthbert's Hospice in Co. Durham has introduced two rapid response teams and if they cannot settle the individual two beds are made available at the hospice for 48 hours – if the individual can go home after that time they do so, and if not quite ready a local nursing home has made available two 'step down' beds
- Hospice at Home provided by Dorothy House Hospice operates a bank of around 30 staff to deal with demand as it arises
- Bradford District Care Trust's Community Specialist Palliative Care Team provide Hospice at Home as well as other 24/7 services
- Use of 'Just in Case' boxes to hold medicines for the last 24 hours of life held in the home were highlighted as a contributing factor for avoiding admissions.

Development of Care Homes

- Focus very much on training of staff in end of life care
- East Sussex has a QIPP Nursing and Care Homes Project with an EoLC work stream
- BANES are introducing a LES that will focus on GPs providing an enhanced service to Care Homes including weekly rounds, use of EoLC tools and support to the care home staff
- Blackpool have a Care Homes Facilitator to help implement GSF or the localised version.



Coordination of care across boundaries and use of Facilitator roles

- Coordination of care was seen as about working together to an agreed plan to provide a seamless service and not about a particular role, whereas the introduction of facilitator roles would appear to be having a positive impact on services
- Within Bradford and Airedale they effectively work across boundaries by having a Managed Clinical Network strategic group for EoLC which is representative of all sectors and aims to provide a seamless service
- In Co. Durham, two Macmillan Discharge Facilitators have been appointed and in the five months in post they have had 181 referrals. In total 144 patients out of the 181 (80%) have achieved their PPD. 27% of referrals were non-cancer
- BANES has appointed a Continuing Healthcare Nurse Assessor who works with the Macmillan SPC lead in the acute sector and 200 referrals were made in the last year with improvements in numbers and rates of discharge
- Two EoLC Practice Development Facilitators have been appointed in Oxfordshire and 92% of PHCTs now use GSF, and in 15 months the percentage of teams using ICP (local version of LCP) has increased from 63% to 88%.

Training to support staff delivering EoLC

- Seen as an investment priority
- Those providing OOHs services must be confident to deliver treatment in the home setting to avoid unnecessary admissions
- Basic palliative care and wider end of life care training for staff in care homes and refresher courses for staff in nursing homes was seen as a key contributor to avoid acute admissions that were unnecessary
- Staff trained in the use of the electronic information sharing systems was a contributing factor.



Data

ONS data is publically available for 08/09 and 09/10 which shows an indicator represented as deaths at home (defined as home, care homes (NHS and non-NHS), and religious establishments) as a percentage of overall deaths by SHAs, PCTs, areas within PCTs as well as core cities and towns. The highest indicator within England for 08/09 was 56.9% and the lowest 22.9%. For 09/10 the highest was 48.3% and the lowest 21%.

Each PCT area has the following range based on publically available ONS Place of Death Indicators released for 2008/09 Q3 to Q2 compared with 2009/10 Q3 to Q2 (Table A1):

Table A1

Areas	08/09	09/10	+/-
Croydon – London Suburbs	28.9%	34.5%	5.6%
Blackpool – Coastal and Country	31.9%	37.4%	5.5%
Bath and North East Somerset (BANES) – Prospering UK	44.5%	47.5%	3.0%
East Sussex Downs and Weald – Prospering UK	43.4%	45.9%	2.5%
Bradford and Airedale – Cities and Services	47.1%	47.3%	0.3%
County Durham – Mining and Manufacturing	40.8%	40.9%	0.1%
Oxfordshire – Prospering UK (Sobell Hospice is on an acute site and therefore gets included in their data returns)	42.1%	41.9%	-0.2%

SWPHO has provided additional data for 2010 drawn from the ONS data and from the NHS Information Centre for each of the seven areas (Appendix C of the main report) broken down by:

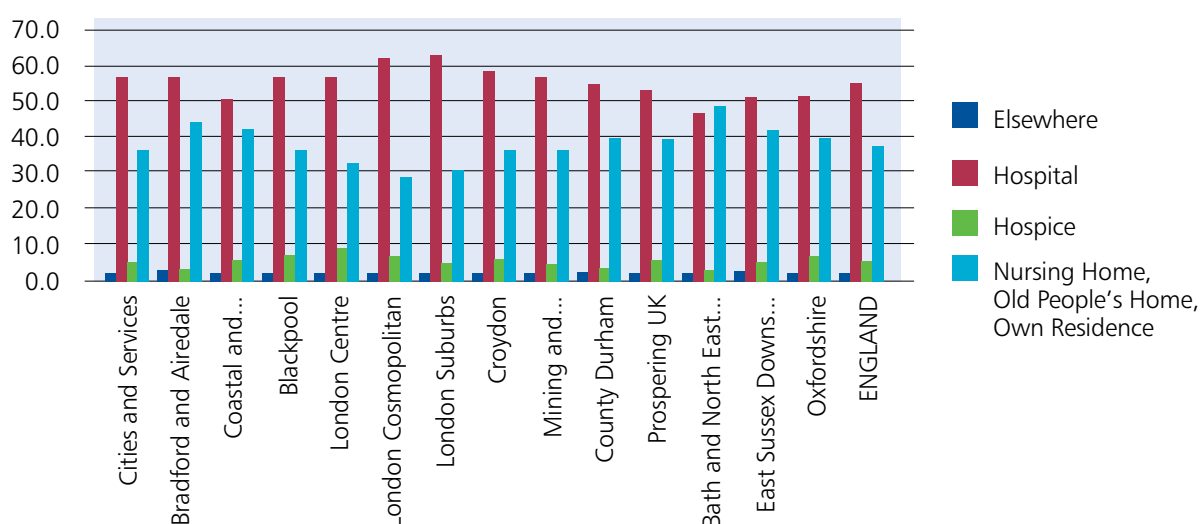
- Number and proportion of deaths broken down by age, gender, deprivation, cause of death and place of death
- Number and proportion of residents (it was agreed that the figures should be based on residents within the PCT area) broken down by age, gender and deprivation category
- The number of GPs broken down by registered population and number of deaths

Comments were received that high levels of deaths at home in rural areas can be due to geography and not necessarily down to good practice. Also increases in deaths outside of hospital may be down to increases in care home deaths and not necessarily deaths at the patient's own residence. In addition, a view was expressed that there is a shortage of good quality care home beds and hospice beds in some inner cities which results in the acute sector playing a larger role and subsequently often being the preferred place of death.

Table B1 and Chart A show the Place of Death based on 2010 data (SWPHO) as a percentage with Nursing Home, Old People's Homes and Own residence categories grouped.

**Table B1**

ONS Group (e.g. PCT)	Elsewhere	Hospital	Hospice	Nursing Home, Old Peoples Home, Own Residence
Cities and Services	1.9	56.7	5.1	36.3
Bradford and Airedale	2.5	50.1	3.3	44.2
Coastal and Countryside	1.8	50.6	5.5	42.0
Blackpool	1.3	55.1	6.7	36.9
London Centre	2.6	56.1	8.9	32.4
London Cosmopolitan	2.5	61.9	6.6	28.9
London Suburbs	1.7	62.8	4.8	30.7
Croydon	1.9	58.3	5.9	33.9
Mining and Manufacturing	1.9	57.0	4.6	36.4
County Durham	2.1	54.8	3.2	39.9
Prospering UK	1.9	53.2	5.5	39.3
Bath and North East Somerset	1.9	46.4	2.9	48.8
East Sussex Downs and Weald	2.1	51.2	4.9	41.8
Oxfordshire	1.8	51.4	6.9	39.9
ENGLAND	1.9	55.0	5.3	37.7

Chart A

When the data provided by SWPHO was compared to the four areas with the highest percentage increase there appeared to be little correlation between achieving high levels of deaths outside of the acute sector and the number of GPs, number of deaths, population profile, classification of deprivation or people resident over the age of 65. Section 3 of the main report looks at these elements in detail.

It was a very small sample to draw conclusions from and that may account for no clear indicators showing any correlation with percentage rises of people dying outside of acute settings.



However, this brief analysis does support the discussions within each of the PCTs that it is more about leadership, processes and communications and a general willingness to support change across the various sectors rather than any significant factor around population, levels of deprivation or numbers of GPs in the area.

Conclusions

From the discussions, information gathered and examples provided the following initial conclusions could be made, however further drilling down into the data and information or reviewing further PCT areas may change or add to those suggested below:

- It would appear that increases in the percentage of individuals able to die outside of the acute setting are not related to differences in data on population, areas of deprivation or the number of GPs in the area or the deaths they deal with on an annual basis
- Geographical differences may impact on the actual numbers as in more rural areas deaths outside of the acute setting are generally higher (which does not necessarily reflect quality services) and within inner cities the acute sector may have a higher number of individuals choosing to die in the hospital
- Strong commissioning and the use of LES and CQUINs to facilitate change are key drivers – commissioners need to drive a whole systems approach e.g. no use improving discharge processes if the community services are not ready
- National EoLC tools, or their local equivalent, are valued and widely in use, but problems are still evident when it comes to electronic information sharing systems
- Education and training of all staff, especially OOHs and those within care homes, are vital if the rate of unnecessary acute admissions decreases and the ability to care for the individual within the home is supported
- Flexible budgets and improvements in community services (both of which are problems wider than end of life services) will also impact on the ability to achieve change
- Improvement and change is largely down to 'champions' and leaders wanting to make a difference and improve quality of services for EoLC. The introduction and use of facilitators in various roles would appear to be achieving tangible results

Next Steps

Some of the areas that may need further consideration nationally and locally are:

- Can we set a realistic measure for achieving PPD;
- What further work should come out of this report, for example:
 - Demographics and GP cover – e.g. is the proximity and concentration of acute hospitals a reason why some urban community based services are not as well developed as in more rural areas
 - Contributions from social care and also from the patient and family perspective were not widely represented in this work
 - Greater exploration of some of the individual CSFs – e.g. more detailed work on potential cost benefit analysis around facilitator roles
 - Identifying 'how to' guides and other supporting materials around the CSFs



SECTION 1

Background

A project between the National End of Life Care Programme (NEoLCP) in partnership with the DH End of Life Care Policy Team and the national QIPP team, with input from the South West Public Health Observatory (SWPHO), was agreed in August 2011. Its purpose was to look more closely at the factors that can contribute to high numbers of people dying outside of acute sector settings. For many this would reflect their preferred place of death (PPD), but not always.

Reliable data on individuals dying in their actual PPD is not readily available and it needs to be recognised that some people want to die in an acute setting for a number of reasons. This is especially so if specialist palliative care services are provided within the hospital or it is not clinically viable for them to be cared for outside of the acute setting.

It was agreed that the contributing factors should be reviewed across a small number of PCTs and a set of critical success factors (CSF) identified. This work was presented to the End of Life Care Programme Board at the end of 2011 and a plan developed whereby the outcomes can be disseminated and utilised for service improvement, to inform commissioning plans and escalate progress.

This work was not undertaken as an academic review based on an existing body of evidence, but reflects the work being undertaken, its impact and the views of over 40 practitioners delivering end of life service across the PCT areas.

Agreed Project Outcomes

The following outcomes were agreed:

- An interim report on emerging themes available by the end of October to inform discussion and test the themes further at the QIPP November workshops;
- A final report for the December 2011 DH EoLC Programme Board outlining proposed Critical Success Factors and recommendations on what would be a realistic % place of death indicator outside of acute settings to aim for. The report will also contain detailed profiles from each of the seven PCT areas that contributed to the work to identify CSFs;
- An action plan to be produced following discussion and guidance from the EoLC Programme Board – work can be used internally to inform planning for workshops for commissioners and providers as well as wider dissemination through EoLC leads and networks highlighting the experience of those implementing change to enable people to die in their preferred place of death, which may include acute settings, care and nursing homes, hospices and community hospitals.

Process

Seven PCT areas were contacted to ask if they would contribute to this work. It was made clear that this project was not about comparing the individual PCT area's performance with the other six, but to learn about the work they were undertaking locally and identifying themes and testing with them the factors they thought were driving change.

Initially lead contacts were identified for each area e.g. SHA EoLC Lead and EoLC Facilitators. On follow up it was recommended that service leads within each of the areas should be contacted which included Specialist Palliative Care consultants and nurses, primary care and community services, hospice leads and PCT end of life care commissioners. A full list of contributors can be found in Appendix A.



In total over 40 people gave up time to either meet or have a telephone call based around a discussion questionnaire sent out to them beforehand (Appendix B). These discussions took place during October and November, with further follow up information and case studies from within the seven areas collated during November.

Each contributor within the PCT area also had an opportunity during November to review the area profile produced based on the discussions, information sent and the profile data supplied by the SWPHO. This enabled them to comment on:

- whether the information reflects their services and make changes as necessary
- if they agree the provisional CSFs identified are those that make a difference
- any further thoughts they may have had that they think could help them accelerate increases in their percentage rates for those dying in their PPD.

Confirmation was received from within each of the PCT areas that the profiles reflected discussions with only minor changes. Note: Where case studies and examples have been provided these have not been edited but left in their original style and format.

All were aware that the information provided may be more widely shared and therefore it was important that they agreed the detail in their profiles.



SECTION 2

Critical Success Factors

There were a number of emerging themes coming out of the discussions and information shared and not all are suitable to become critical success factors, but should be considered when considering change.

- **Some are intangible.** In many cases where improvements are beginning to be implemented and show improvement it is down to the drive and enthusiasm of an individual, or a team of individuals, which is hard to measure and has a certain risk attached should a key individual move on.
- **No one model fits all.** It was raised on a number of occasions about the geographical impact on PPC/PPD. In more rural communities more use is made of primary and community care services as the distance to travel to an acute hospital can be problematic especially during a hard winter. Conversely a view was expressed that in urban areas, especially London, that the acute sector play more of a role as facilities such as care homes and hospices are often located in more suburban areas.
- **Community Services.** All believed improvements to community services were needed, as change will only happen if it is a whole systems change.
- **Current Boundary and Organisational Change.** Also of concern are the current boundary and reorganisational changes and the uncertainty that brings around funding, commissioning and delivery models. It has made progress more difficult and when working across sectors has flagged uncertainty to commit to the future.
- **Need to raise the quality of care.** Overall there was a strong message that by enabling individuals to die in their preferred place of death it should not just be about productivity but also about quality of care.

The factors that are considered critical are (not ranked):

- Strong commissioning and clinical leadership
- Use of nationally recognised drivers that attract payment – LES and CQUINs
- Flexible budgets and care packages
- Use of nationally recognised tools or their local equivalent – ACP, GSF, LCP, PPC, ADAs and CHC Fast Track Pathway
- Shared electronic information systems
- Clearly defined access to 24hr cover
- Development of Care Homes
- Use of facilitator roles and coordination of care across boundaries
- Training to support staff delivering EoLC

The following sections reflect the discussions and include examples of work that has made a difference to services, and many can be seen to be interrelated throughout the sections.

These examples are only representative of a small amount of the work undertaken in the PCT areas and full area profiles in Appendix D provide more detail on work mentioned below as well as other supporting work.

(Note: Where case studies and examples have been provided these have not been edited but kept in their original style and format within the profile).



Strong Commissioning and Clinical Leadership

Where a PCT commissioner with experience and knowledge about the whole system approach exists and works in partnership with clinical leaders it is easier to reinvest and redesign services across boundaries.

It was evident where the PCT EoLC Commissioner/Lead was involved in the discussions that initiatives moved forward in a coordinated way. **BANES, Croydon, Blackpool and Oxfordshire** leads all made major contributions to this project. An example of PCT leadership was given in **Croydon** where work with care homes was funded by time limited charity monies but the PCT recognised the positive impact this was making and took over the funding with the view 'invest to save'. The PCT commissioner in **BANES** is moving on to another job in CHC, but her colleagues say that much of the progress in **BANES** around registers, LES, CQUINs and cohesive working across sectors would not have happened as quickly without her.

Clinical leadership with the vision to make things happen is important to achieve change. Many of those clinicians who contributed are leaders of change, but may not identify themselves as such.

With the new CCGs it will be essential they inherit an audit of the whole system supporting end of life care that clearly sets out what the agreed priorities are. Getting primary care and community care right for end of life was seen as key driver for change across the wider system. GP Facilitators, LCP and GSF facilitators as well as local champions on the ground have proved beneficial to local change and will have an important role in getting people to work as a 'wider team'. **East Sussex** has appointed an EoLC QIPP lead (covering all Sussex) who is attributed to taking forward a range of activities.

Use of nationally recognised drivers that attract payment

Commissioners can utilise recognised drivers for change such as CQUINs and Local Enhancement Schemes (LES) through informed negotiation engendering trust and cooperation between all partners. Often without payment engagement by GPs can be limited, so taking a view that 'invest to save' can be seen as proactive commissioning.

In **Croydon** a LES was developed with GPs to assist patients to achieve their PPC and reduce hospital admissions which resulted in 95% of the registered population being covered by practices signed up to LES. One of the benefits of this in 2010/11 was the prevention of over 300 hospital admissions due to activities by GPs.

Within **BANES** work has recently been undertaken to support GPs in developing enhanced services for Care Homes with Nursing (CHWN) through a LES. The response has been very positive and in November over half the practices had expressed an interest that will cover a significant number of care home beds. Also CQUINs have been introduced for the Acute Trust which includes an indicator on 'Patient dying in the place of their choice' and others to support EoLC schemes relating to training, registers and reduction of deaths in hospital for over 65's. CQUINs are also in place for the CHC provider.

Flexible budgets and care packages

Joint budgets to facilitate seamless care across boundaries was raised a significant number of times and caused frustrations across both health and social care when delivering an agreed care package was delayed. Ring fenced funding generally was also often seen as a disincentive. For example if treatment and therapeutic budgets could be used to fund care at home, if appropriate, without the background concern that the budget would be cut the following year, it would facilitate greater flexibility.

Significant support was given for joint budgets so that a care package can be put in place for an individual without the issues and time delays around accessing social care funding. This was not just about services by carers but also around equipment availability. This would facilitate greater flexibility to reflect changes in the care package to support changing conditions with the patients

Many thought that once community care improvements were delivered it would have an impact on fast track continuing care, 24 hour access to services as well as maximising use of ACP and other tools.



Use of nationally recognised tools or their equivalent

a) Continuing HealthCare Fast Track Tools, rapid discharge and use of LCP, GSF and PPC

The use of some or all of these tools were mentioned by all areas with some acknowledging that take up levels are varied. They contributed to clear protocols and understanding of processes and actions needed across the boundaries. Continuing care packages available for those discharged using the fast track process have facilitated more individuals being moved to their preferred place of care, but a grey area surrounds those who do not meet the criteria. However sometimes discharge is delayed if the community services are not in place e.g. equipment sent out quickly.

The use of DNs to deliver services such as supporting the fast track continuing care packages, and general support for end of life care, was a concern raised by a number of contributors. While DNs are highly valued, with the length of hospital stays reducing across all clinical areas their services are under pressure with only around 10,000 DNs in England and the training numbers reducing. The pressure on DN services can be a delaying factor in discharges. Differing skill mix and up skilling generalists will have to be a future consideration as DN numbers diminish.

b) Advance Care Planning (ACP) and After Death Analysis (ADA)

Having the conversation early enough about preferred place of care and death, and other issues such as DNACPR, and ensuring there is an outcome of statement and wishes delivered through an ACP process known to all those involved in the close care of the individual was a main theme running through discussions. However, handling of individuals and their carers at such a sensitive time is important and it needs to be acknowledged that not everyone may want to take part in the ACP process. Generally using the ACP process and its outcomes was seen as the main element to delivering preferences for the individual.

Utilising ADAs (GSF or local equivalent) as an audit tool allowed a review of progress and influenced further service developments through learning why and understanding the reasons an individual may not have died in their preferred place. This may be due to a number of valid reasons.

In Croydon as part of the LES, GP practices were asked to complete an after death analysis for each patient registered with the practice. In 2010/11 1800 ADAs were submitted which is 2/3rds of the expected deaths.

c) EoLC Resource Pack

Trinity Hospice in Blackpool has developed an EoLC resource pack that is available on their website (see profile for details). The actual pack includes three sections; core resources (including localised NW EoLC Model, Primary Care Prescribing Guidance, Just in Case Prescribing Card, Network Prescribing Guidance and GMC booklet on decision making at the end of life), end of life tools (including GSF and prognostic indicators, PPC and LCP), and additional resources such as Trinity info, Macmillan info, Dying matters info. The pack is given out to all GP surgeries. Funding has just been agreed to extend the packs for all other end of life health care professionals working in primary and secondary care.



Shared Electronic Information Systems

Electronic sharing of information (i.e. EoLC registers) about the individual was considered critical to enable avoidance of unnecessary admissions as well as ensuring that the individual's wishes were acknowledged and acted upon if clinically possible. Whatever system is adopted locally it needs to cover acute, primary care, community care services, OOHs, hospices and ambulance services and any others as locally determined.

Whilst some thought that it could also include care homes it was generally agreed that significant work needed to be undertaken in the care home sector and the responsibility for ensuring that a resident in a care home was on the register should lay with either the GP, District Nurse or Community Matron. Staff attending an emergency call at a care home must have access to the register.

Only one of the areas (**BANES**) had been involved in the Locality Registers Pilots. Considerable effort and investment has been made in **BANES** that includes supporting education and training which started within primary care and the acute trust will be in the final phase. They felt that it does help to coordinate packages of care, and in one care home it has resulted in no avoidable admissions since introduced.

All had some form of electronic system although coverage often excluded acute hospitals.

Where an integrated system does exist (Weston Area Health Trust and Weston Hospicecare) results shown are promising. The Ipsos MORI 'End of Life Locality Registers' evaluation – final report (June 2011) gives a more detailed view of the application of registers which has been reflected by the contributors to this project. Patient consent and information governance still seem to need further clarity.

Clearly defined access to 24 cover

Clearly defined 24 hour services were identified as a necessity to avoid confusion for staff, individuals and their carers. A single point of access where the call handler can either deal directly or take details and pass them on to the relevant service was a model that seemed beneficial to individuals and their carers. It was agreed that staff delivering OOHs services for patients at the end of their lives must feel confident to treat the patient in their home to avoid hospital admissions where possible, and this must be done through focussed, protected time development opportunities.

The range of differing models for 24hr cover is demonstrated in the individual PCT area profiles Appendix D.

As an example the model in **Bradford and Airedale** was clearly defined and included:

- GPs during the day and OOH GP at other times
- SPC team 24-hour
- Hospice at Home 8am to 10pm then a night time DN service
- Marie Curie providing night time care as well
- Where fast track care package included social care sessions there is the flexibility to substitute additional palliative care sessions if necessary.

The flexible response service RISE (Rapid Intervention Service for EoLC) has been introduced in **Oxfordshire** and provides care and support by HCAs day or night for up to six days. RISE aims to assess within 4 hours of referral if made before 6pm.

Hospices have a major role in providing 24 hour support through dedicated teams and telephone support as well as training for OOH medical staff. St Cuthbert's Hospice in **County Durham** is introducing two rapid response teams in the new year as a joint project with the PCT and Marie Curie that will comprise a qualified nurse and HCA trained in palliative care. If the rapid response teams cannot settle the individual the hospice is making two unregistered assessment beds available for 48 hours and after that time if they cannot return to their home or care home immediately an agreement has been reached with two nursing homes that they can go to 'step down' beds in the nursing home for a short period.



Sue Ryder Manorlands Hospice in **Bradford and Airedale** does not operate a waiting list. A single referral form is used and all referrals reviewed at 9am each day – this has proven to keep the process moving quickly.

Hospice at home services contributed significantly to avoiding admission to an acute hospital. They support individuals usually over the last 14 days and vary from being 24 hour cover to sessions of a minimum of 3 hours depending on the care package. Differing models have been developed which include provision by Hospices such as the Dorothy House Hospice model in **BANES**, to being provided by Palliative Care Services within a Trust such as **Bradford and Airedale's** Bradford District Care Trust's Community Specialist Palliative Care Team. Dorothy House Hospice has adopted a flexible approach to staffing H@H by employing a bank of about 30 staff on flexible contracts to meet demands as they arise.

Use of 'Just in Case' boxes holding agreed medicines that may be needed in the last 24 hours of life held in the individuals place of residence were highlighted as an element that contributed to avoidance of unnecessary admissions, however the delay in making these available is often around the initial cost of the boxes. JIC should be noted on the EoLC register.

A number of people did raise the issue of how the '111' service will relate to 24/7 cover.

Development of Care Homes

The majority supported the view that if staff in care homes were supported to feel more competent and confident to provide basic palliative care to individuals it should result in fewer unnecessary acute admissions and enable rapid discharge after an acute episode back to the care home to enable individuals to die, if that is their choice. However, it was stressed that admissions to hospital from care homes for acute episodes are often necessary, so achieving the correct balance is important.

Therefore investment in training of staff within care homes is seen as a priority.

East Sussex is taking forward a QIPP Nursing and Care Homes project covering 400 Care Homes. The EoLC element is being led by the hospices and will use EoLC emergency admissions data and urgent care data on Care Home Residents admitted to hospital to assess support needs. Once identified a multi-disciplinary approach will be taken to support the Care Home to reduce admissions and they will be encouraged to utilise EoLC tools.

Use of LES such as that mentioned previously within **BANES** will focus on GPs input to care homes with nursing (CHWN) where they will undertake an enhanced service including a weekly 'ward round' with new residents within five days of admission, assessment/management and review within 5 days of a resident returning from hospital admission, use of EoLC tools, as well as provide support to care home staff and community matrons.

Blackpool PCT employs a Care Homes Facilitator whose role is to support development within Care Homes. GSF development is offered and for those not undertaking GSF an educational model has been developed locally which is adapted to meet the needs of individual homes and clients and is based on the North West EoLC Model.

Croydon PCT now funds an EoLC facilitator to change the culture and practice of end of life care in Nursing Care Homes to improve the number of residents able to stay in the NCH to die.

Coordination of Care across boundaries and Use of Facilitator roles

There was a clear difference expressed between the coordination of services and the facilitator role who was focussed on one area, such as GSF, LCP or discharge activities.

Coordination was about the need to ensure information was shared, working as wider teams such as MDTs with social care engagement and if appropriate individuals, their carers and other closely involved in their care was encouraged. Ensuring differing care sectors and providers had an agreed strategic plan for end of life care that offered a seamless service to the individual and their families.



This would include timely access to equipment and other services within the care package as they could cause unnecessary delays, for example if equipment is not readily accessible and available not only can it hold up discharges but can also lead to unnecessary admissions e.g. lack of commodes, hospital beds in the home, hoists etc.

Within **Bradford and Airedale** three elements support joint working and good communications:

- the first is the Bradford Community Specialist Palliative Care Team who also provide Hospice at Home services,
- the second is the Managed Clinical Network strategic group for end of life care who are considered a key element in providing a seamless service
- in addition, the third is the rotation of SPC consultant posts across acute, community and hospices.

More facilitator roles to coordinate discharge, both within the acute setting and in continuing care services, from the acute setting to preferred place of care/death were encouraged as they seen to be making a significant impact.

In **County Durham** two Macmillan Discharge Facilitators were appointed in the spring 2011 and positive results are already being identified. These facilitators are supported by a group of Macmillan carers in the community. A recent internal report on the five months the MDFs have been in post has shown that from 181 referrals 155 patients were discharged. Six patients who were discharged did not achieve their PPD and other arrangements were made with their agreement. In all 144 patients out of the 181 (80%) achieved their PPD including those who chose to die in the acute hospital. Of the 181 referrals, 27% were non-cancer. These results if sustained will have a significant impact on patient experience at the end of their lives.

In **BANES** a Continuing Healthcare (CHC) Nurse Assessor works closely with the Macmillan SPC lead in the acute hospital and the numbers and rate of discharges has improved. Last year she dealt with 200 referrals from the acute service. The assessor receives a fax informing her that a patient has reached a terminal phase and she contacts the hospital to discuss details on their wishes of the patient and family and arranges to meet with them the same day if possible. They are advised about funding and care available and the likelihood or any reassessment if the patient's condition changes further. She will also speak to OT, Physiotherapy and check availability of equipment and make sure everything is in place. The palliative care team and the DN are contacted and the DN should visit the patient within 24 hours and take over the care. If a care home is chosen as PPC then she provides the families with a suitable list for them to visit, and then she can then check the funding agreement. Her role also includes advising the acute hospital if she believes it is not appropriate to move an individual if facilities are not suitable or cannot be made available.

Two EoLC Practice Development Facilitators have been appointed in **Oxfordshire** to take forward uptake of national tools resulting in 92% of PHCTs using GSF individualised to each team and from January 2010 the percentage of teams using ICP (Oxfordshire version of LCP) had increased for 63% to 88% in April 2011.



Training to support staff delivering end of life care

This underpins most of the initiatives mentioned by contributors and training was a significant investment priority. Some of the training and development required highlighted by the PCTs included:

- Within acute settings development for generalist staff and specialist in other clinical areas especially around moving from intervention to palliative care
- Communication skills at all levels
- ACP, LCP, GSF and PPC or local equivalent across all boundaries for staff working closely with the individual including GPs
- Basic palliative care and wider end of life care for staff in care homes and refresher course for staff in nursing homes
- Induction for staff working as facilitators so that they know the areas they are covering and all the services across boundaries that they need to be aware of to deliver a full care package
- Use of electronic information sharing systems.

Resources to support training are critical to the delivery of quality services across boundaries. With the focus on mandatory training taking a priority, training for some groups of professionals and others in end of life care cannot be guaranteed. Some felt that mandatory training in end of life care was the way forward but others felt that it could then become a 'tick box' exercise.

It should be acknowledged that in most areas, significant funding has been made available for end of life training and numerous activities led by hospices and PCTs were highlighted. National learning packages such as e-ELCA, which is free to NHS staff and social care staff as well as GPs and Hospices, has been used to support local training but due to early access issues has stopped some organisations from incorporating it within their local training schemes.



SECTION 3

Related Data

ONS data is publically available for 08/09 and 09/10 which shows an indicator represented as deaths at home (defined as home, care homes (NHS and non-NHS), and religious establishments) as a percentage of overall deaths by SHAs, PCTs, areas within PCTs as well as core cities and towns. The highest indicator within England for 08/09 was 56.9% and the lowest 22.9%. For 09/10 the highest was 48.3% and the lowest 21%.

The latest provisional ONS rolling quarterly data has now been made available to this project for 10/11 Q2 to 11/12 Q1.

SWPHO has provided additional data drawn from the ONS data and from the NHS Information Centre for each of the seven areas (Appendix C) broken down by:

- Number and proportion of deaths broken down by age, gender, deprivation, cause of death and place of death
- Number and proportion of residents (it was agreed that the figures should be based on residents within the PCT area) broken down by age, gender and deprivation category
- The number of GPs broken down by registered population and number of deaths

The following seven PCT areas (pre clustering) have contributed to the project. Areas were chosen to represent either significant proportional increases, overall levels at the higher end range for England and to reflect differing profiles such as prospering UK, coastal and countryside, mining and manufacturing as well as city and London suburbs.

Comments were received that high levels of deaths at home in rural areas can be due to geography and not necessarily down to good practice. Also increases in deaths outside of hospital may be down to increases in care home deaths and not necessarily deaths at the patient's own residence. In addition a view was expressed that there is a shortage of good quality care home beds and hospice beds in some inner cities which results in the acute sector playing a larger role and subsequently often being the preferred place of death.

Each area has the following range based on publically available ONS Place of Death Indicators released for 2008/09 Q3 to Q2 compared with 2009/10 Q3 to Q2 (Table A):

Table A

Areas	08/09	09/10	+/-
Croydon – London Suburbs	28.9%	34.5%	5.6%
Blackpool – Coastal and Country	31.9%	37.4%	5.5%
Bath and North East Somerset (BANES) – Prospering UK	44.5%	47.5%	3.0%
East Sussex Downs and Weald – Prospering UK	43.4%	45.9%	2.5%
Bradford and Airedale – Cities and Services	47.1%	47.3%	0.3%
County Durham – Mining and Manufacturing	40.8%	40.9%	0.1%
Oxfordshire – Prospering UK (Sobell Hospice is on an acute site and therefore gets included in their data returns)	42.1%	41.9%	-0.2%



The latest provisional ONS rolling quarterly data for Quarter 2 2010/11 to Quarter 1 2011/12 made available for the project, highlights the following results (Table B) for each of the areas:

Table B

Areas	09/10 Q2 to 10/11 Q1	10/11 Q2 to 11/12 Q1	+/-
Croydon	34.6%	35.8%	1.2%
Blackpool	37.4%	37.5%	0.1%
Bath and North East Somerset (BANES)	47.5%	49.9%	2.4%
East Sussex Downs and Weald	46.0%	47.0%	1.0%
Bradford and Airedale	47.3%	48.6%	1.3%
County Durham	41.0%	43.3%	2.3%
Oxfordshire	41.9%	43.0%	1.1%

GP Provision

The two charts below have been produced from the data in Appendix C and show the average number of people per GP FTE and the average number of deaths per GP FTE for 2010 by ONS PCT Group and for each of the above seven areas within their grouping.

Chart 1 – Average number of people per GP FTE

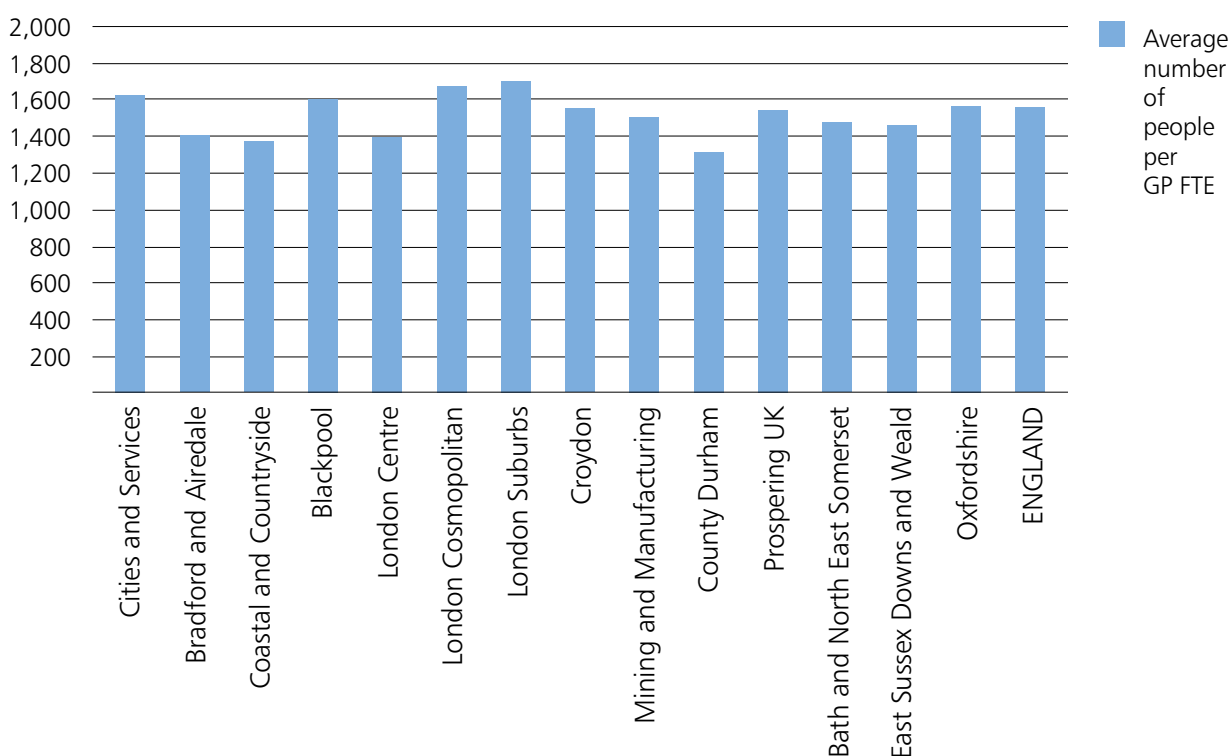
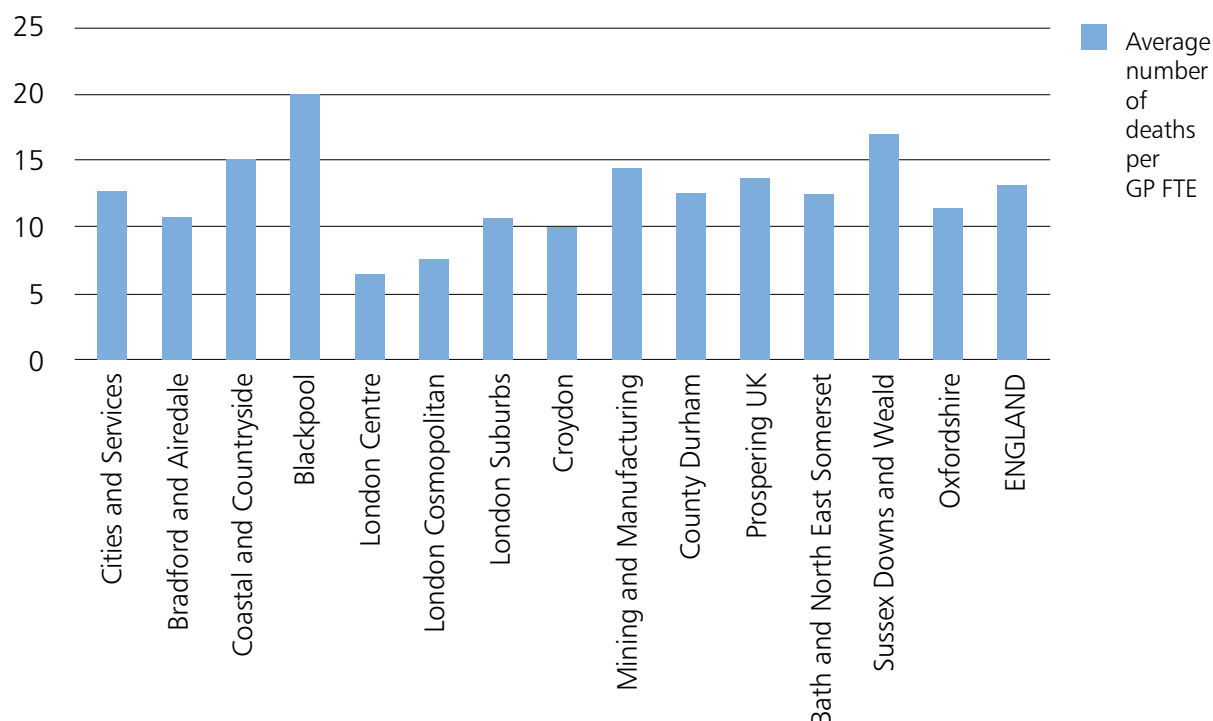




Chart 2 – Average number of deaths per GP FTE



When comparing these figures for the four areas showing the highest % increase for deaths at home on Table A the following is evident:

- Croydon – has a lower average number of people per GP FTE than its ONS Group and about the same as England, has the same average number of deaths per GP FTE as its ONS group but is lower than England
- Blackpool – has a higher average number of people per GP FTE than its ONS group and England, has a higher average number of deaths per GP FTE than its ONS group and England
- BANES – has a lower average number of people per GP FTE than its ONS group and England, has a lower average number of deaths per GP FTE than its ONS group and is the same as England
- E. Sussex Downs and Weald – has a lower average number of people per GP FTE than its ONS group and England, has a higher number of deaths per GP FTE than its ONS group and England

This is only a small sample but there does not seem to be a clear correlation between the figures on Table A and the number of GPs and the population they cover and number of deaths.

Population Profile

The following charts have been extracted from data in Appendix C. They cover the age profile (%) for each of the seven areas as well as the ONS PCT Group and the % within each deprivation classification.

Chart 3 – % Age Profile (2010)

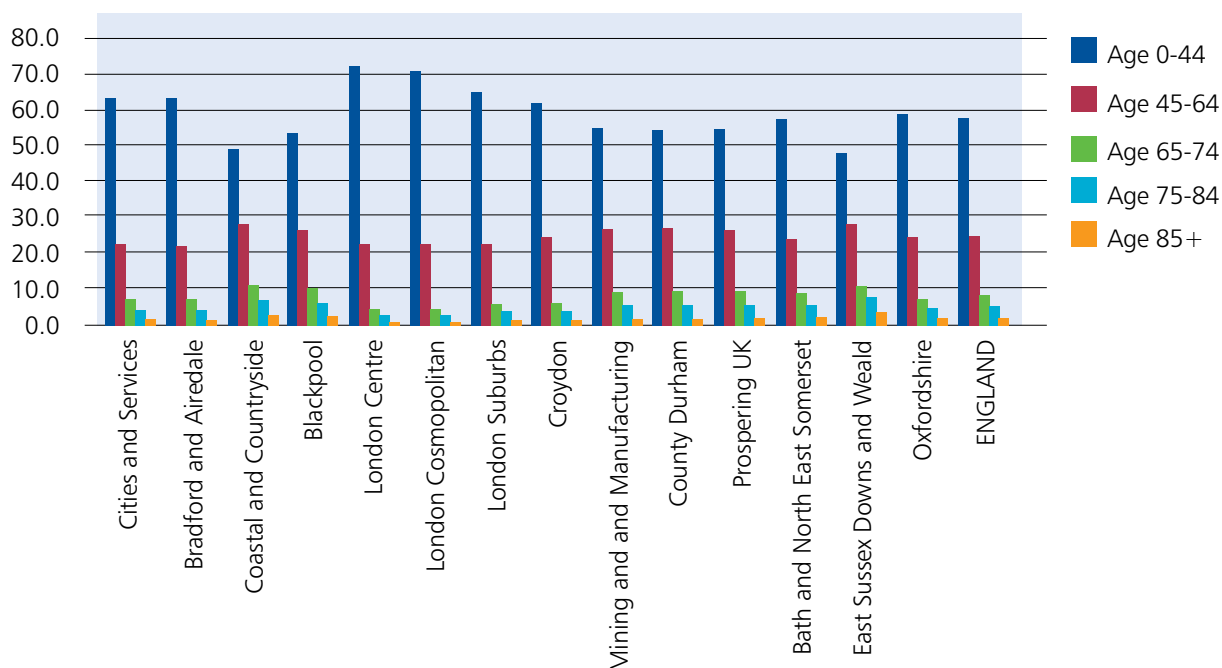
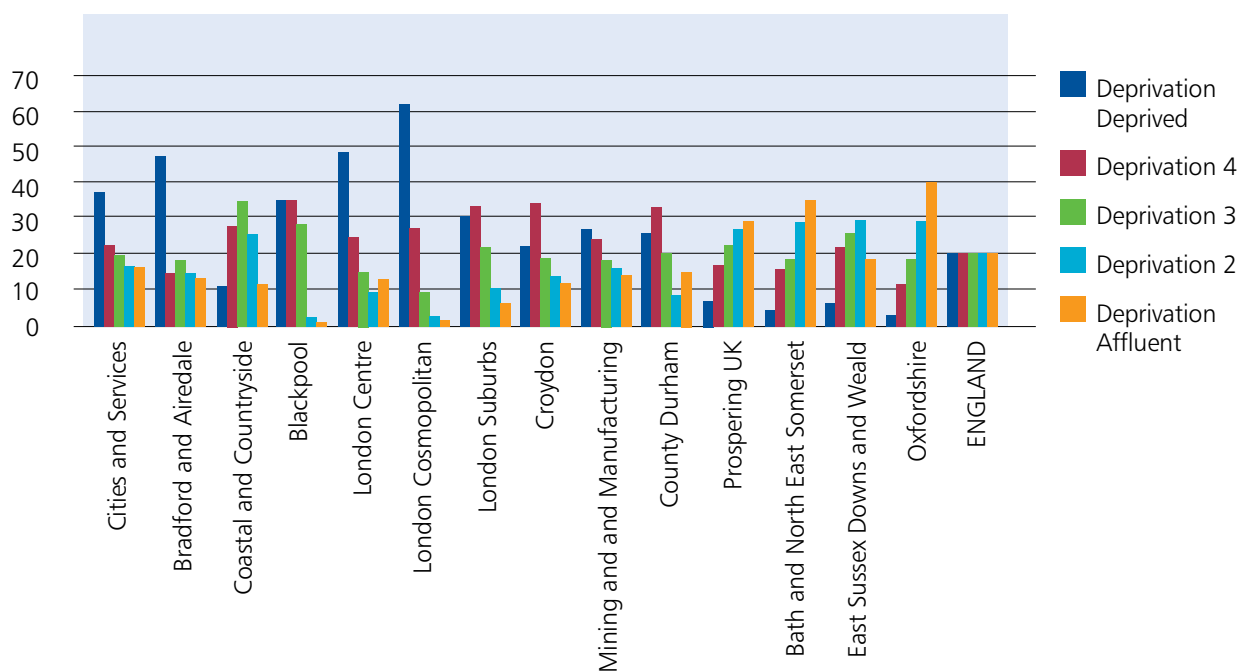


Chart 4 – Deprivation category shown as a % (2010)



When comparing these figures with the four highest % increase areas for deaths at home shown on Table A the following is evident:

- Croydon – has a higher percentage of residents aged over 65 than its ONS group and lower than England, and a lower percentage categorised as deprived/4 than its ONS group but higher than England
- Blackpool – has a lower percentage of residents aged over 65 than its ONS group and higher than England, and a higher percentage categorised as deprived/4 than its ONS group and England
- BANES – has a slightly lower percentage of residents aged over 65 than its ONS group and slightly higher than England, and a lower percentage categorised as deprived/4 than its ONS group and considerably lower than England
- E. Sussex Downs and Weald – has a higher percentage of residents aged over 65 than its ONS group and England, and a higher percentage categorised as deprived/4 than its ONS group but considerably lower than England.

This is only a small sample but there does not seem to be a clear correlation between the figures on Table A and the numbers of residents over 65 in the areas or the level of deprivation.

Death Profile

The following charts have been extracted from data in Appendix C. They cover the % of deaths by deprivation category and place of death as a percentage of all deaths.

Chart 5 – % of Deaths by Deprivation Category (2010)

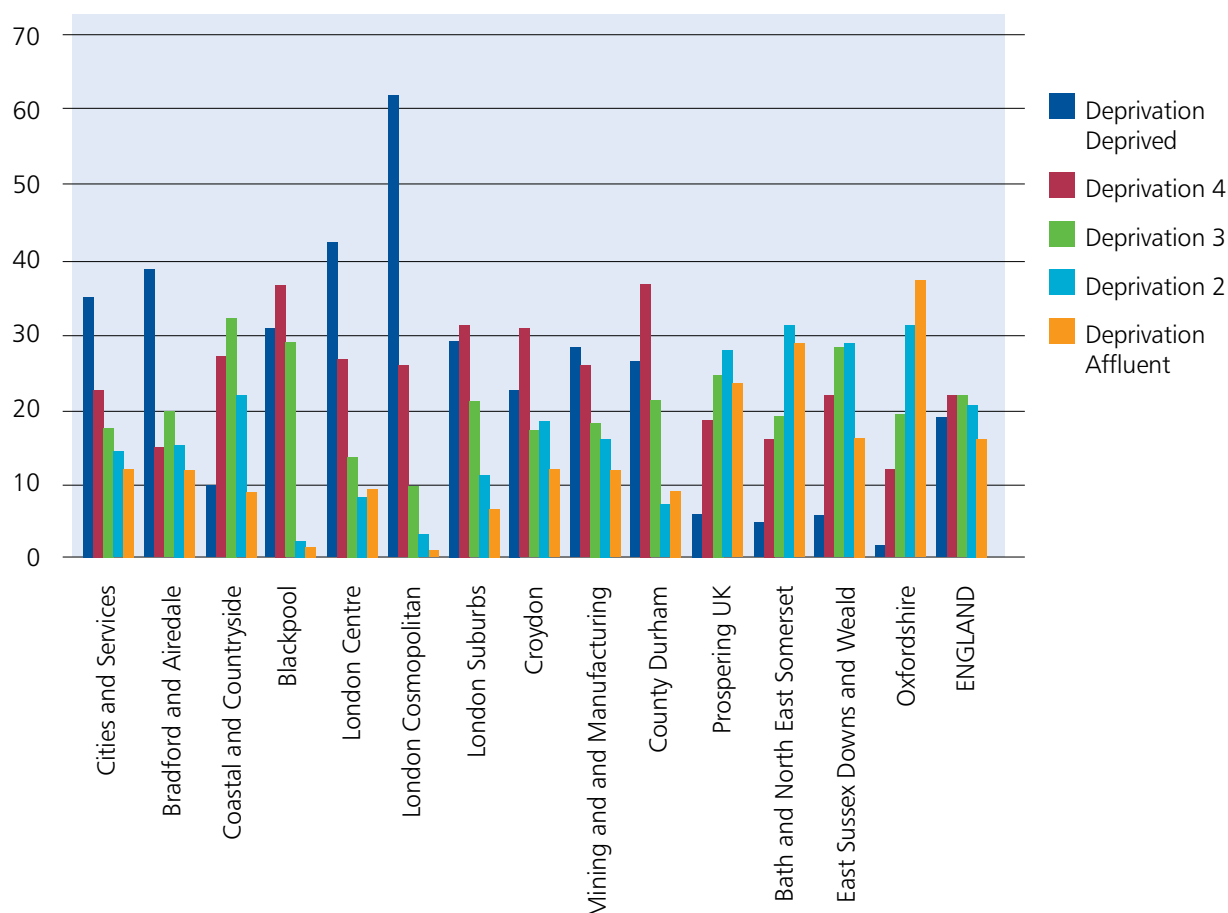
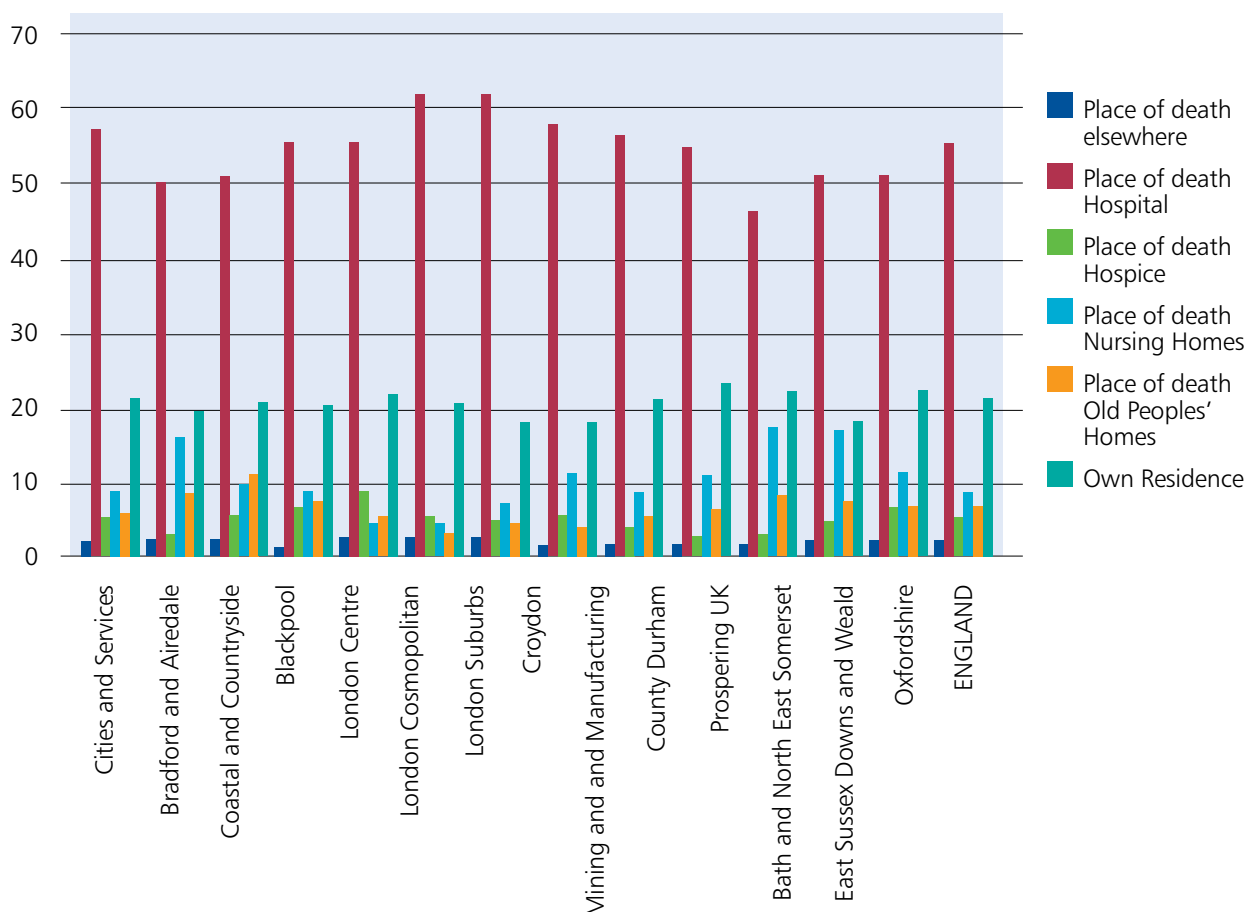


Chart 6 – % Place of Death as a % of all deaths



When comparing the above information with the seven areas only Croydon has percentages of hospital deaths higher than the England figure. All others were lower except Blackpool which was very slightly above the England figure. All areas except Co. Durham have deaths in own residence broadly comparable with the England figure. Co. Durham has at least 2.2% higher deaths in own residence than the England average.

Only BANES, Oxfordshire, and E.Sussex Downs and Weald (all categorised as 'Prospering UK') have a lower % of deaths within the 'deprived' category than the England average.

This is only a small sample but no clear indicators are emerging around areas of deprivation category or place of death.

Summary

This has been a very small sample that may account for no clear indicators showing a correlation with percentage rises of people dying in in their PPD and the data looked at in Appendix C. However, this brief analysis does support the discussions within each of the PCTs that it is more about leadership, processes and communications and a general willingness to support change across the various sectors rather than any significant factor around population, levels of deprivation or numbers of GPs in the area.



Appendix A – List of Contributors

The following people gave up their time for this project for which NEOFPC are extremely grateful and for the openness with which they shared information. All showed high levels of motivation and enthusiasm for achieving change in end of life services and without their work many of the service improvements highlighted would not have happened or progressed as quickly.

Croydon PCT Area

Jacqueline Goodchild	Senior Commissioning Manager Older People and Long Term Conditions, Croydon Borough Team
Rob George	SHA EoLC Lead
Anna Butt	End of Life Care Facilitator, Croydon Residential Homes, St Christopher's Hospice
Jo Hockley	Nurse Consultant, Care Home Project Team, St Christopher's Hospice.
Penny Hansford	St Christopher's Hospice

Blackpool PCT Area

Andrea Doherty	Lead Cancer Nurse – EoLC Project Lead – Blackpool Teaching Hospitals NHS FT
Lorraine Tymon	EoLC Project Coordinator – Blackpool Teaching Hospitals NHS FT
Kathryn Smith	Clinical Lead for End of Life Care – NHS Blackpool PCT
Janet Purdie	Care Home Facilitator – NHS Blackpool PCT
Dr Sarah Wenham	Community Consultant – Trinity Hospice
Dr Susan Salt	Medical Director – Trinity Hospice
Dr Jane Huttley	Clinical Director – Trinity Hospice
Dr Andrea Whitfield	Hospital Consultant in Palliative Medicine.

BANES PCT Area

Sue Townley	Project Manager, EoLC Commissioning – BANES PCT
Rachel Davis	SPC Nurse at RUH/ EoLC Facilitator
Karen Riddle	CHC Nurse Assessor – SIRONA Care and Health
Sarah Whitfield	CE, Dorothy House Hospice

East Sussex

Karen Devanny	SHA EoLC Lead
Kay Muir	Programme Lead, End of Life Care – NHS East Sussex Downs and Weald, NHS Hastings and Rother

Bradford and Airedale

Charlotte Rock	Macmillan CNS Palliative Care Bradford Teaching Hospitals
Fiona Hicks	Consultant in Palliative Care – York and Humber SHA EoLC Lead
Belinda Marks	Clinical Lead Palliative Care Service – Bradford District Care Trust
Steve Davison	Care Services Manager – Sue Ryder Manorlands Hospice
June Toovey	Nurse Director – Yorkshire Cancer Network



County Durham

Colette Hawkins	Palliative Care Consultant – University Hospital of N Durham
Kay McAlinden	Macmillan Lead Nurse, County Durham & Darlington NHS Foundation Trust
Elizabeth Kendrick	GPwSI Older people and Chair End of Life Clinical Innovation Team NHS North East County Durham & Darlington NHS Foundation Trust
Lauren Shepherd	Macmillan Discharge Facilitator
Angela Dinsdale	CE St Cuthbert's Hospice

Oxfordshire PCT

Bee Wee	consultant in palliative medicine – Sir Michael Sobell House
Kay Francis	community matron
Patricia Glynn	community matron
Lizzie Coss	community matron
Ali Flint	specialist palliative care clinical nurse specialist
Nicky Peregrine	specialist palliative care clinical nurse specialist
Geraldine O'Meara	specialist palliative care clinical nurse specialist
Fi Elbourne	specialist palliative care clinical nurse specialist
Kate Butcher	practice development facilitator for EoLC
Claire Britton	practice development facilitator for EoLC
Bernadette Ross	director of nursing, Katharine House (independent hospice)
Neale Conner	occupational therapist, specialist palliative care
Laura Carter	commissioner NHS Oxfordshire PCT
Lucy Sutton	Associate Director for End of Life Care Programme and AQP Lead – NHS South Central

Others

Julian Abel	Consultant in Palliative Care, Weston Area Health Trust and Weston Hospicecare
Sue Dewar	Lead Midhurst Macmillan Services, West Sussex



Appendix B – Discussion Questionnaire

Identifying Critical Success Factors that contribute to individuals being able to die outside of acute sector settings if that is their preferred place of death – Information Request

PCT/Core City Area:

<p>1. Local Information about PPD rates:</p> <ul style="list-style-type: none"> do you monitor actual place of death against PPD, if so have you got local figures you can share with us? do you know how many people have their PPD as within the acute sector?
<p>2. What triggers an individual as being on the eolc pathway e.g. use of Locality Registers?</p>
<p>3. Services in the area:</p> <ul style="list-style-type: none"> Local Hospitals – split by providing eolc/palliative care and those that do not – are there any hospice or community beds situated on an acute site which may skew the figures? Models of Specialist Palliative Care Provision including Hospices 24/7 Support available for eolc e.g. District Nursing Services supporting eolc, Domestic/social care services supporting eolc, Dedicated teams (NHS and independent) supporting eolc
<p>4. MDT arrangements in place</p>
<p>5. Protocols and tools in place:</p> <ul style="list-style-type: none"> Use of pathways – GSF, LCP and PPC ACP Clinical governance for example DNACPR Care after Death protocols
<p>6. Evidence of joint working with social care for individuals on the eolc pathway</p>
<p>7. Evidence of joint working with the voluntary sector on eolc</p>
<p>8. EoLC Workforce development activities – communication skills training, eLearning, local developments</p>
<p>9. Overall end of life care leadership/partnerships in place</p>
<p>10. Other related programmes or projects undertaken</p>
<p>11. What do you see as the CSFs and what else could be done to help accelerate increases for people enabled to die in their PPD.</p>



Appendix C

SWPHO data for the seven PCT Areas



Death profile, PCTs & England 2010 Number of deaths

PCT	Bath and North East Somerset	Blackpool	Bradford and Airedale	County Durham	Croydon	East Sussex and Weald	Oxfordshire	ENGLAND
Age								
0-44	47	82	266	191	143	108	191	19,108
45-64	166	308	611	721	376	374	558	59,746
65-74	238	343	708	894	370	525	742	73,970
75-84	479	556	1,331	1,663	710	1,230	1,411	138,449
85+	739	591	1,377	1,640	897	1,832	2,015	169,743
Gender								
Male	792	962	2,075	2,469	1,236	1,888	2,317	222,366
Female	877	918	2,218	2,640	1,260	2,181	2,600	238,650
Deprivation								
Deprived	62	581	1,675	1,383	559	177	112	89,948
4	277	683	618	1,816	762	878	574	100,535
3	326	550	857	1,056	436	1,169	966	100,489
2	516	44	638	363	449	1,183	1,517	94,349
Affluent	488	22	50	491	290	662	1,748	75,595
Cause of Death								
Cancer	464	531	1,126	1,449	657	1,113	1,466	129,523
Cardio-vascular	486	512	1,313	1,413	744	1,379	1,284	134,096
Other	542	543	1,233	1,497	704	1,071	1,513	134,530
Respiratory	177	294	621	750	391	506	654	62,867
Place of Death								
Elsewhere	31	25	107	109	47	87	88	8,832
Hospital	775	1,036	2,149	2,802	1,455	2,082	2,528	253,575
Hospice	48	126	140	162	148	198	339	24,651
Nursing Homes	302	169	690	535	286	663	539	42,750
Old People's Homes	141	139	352	322	96	290	348	34,916
Own Residence	372	385	855	1,179	464	749	1,075	96,292
All Deaths	1,669	1,880	4,293	5,109	2,496	4,069	4,917	461,016



Death profile, PCTs & England 2010 Percentage of deaths

ONS Group (e.g. PCT)	Cities and Services	Bradford and Airedale	Coastal and Countryside	Blackpool	London Centre	London Cosmopolitan	London Suburbs	Croydon
Age								
0-44	5.1	6.2	2.8	4.4	7.7	9.3	6.4	5.7
45-64	14.3	14.2	11.1	16.4	17.0	17.8	14.6	15.1
65-74	16.7	16.5	15.1	18.2	16.9	17.6	15.7	14.8
75-84	29.9	31.0	29.4	29.6	27.5	27.6	28.3	28.4
85+	34.1	32.1	41.6	31.4	30.8	27.8	35.0	35.9
Gender								
Male	48.6	48.3	47.4	51.2	51.5	52.6	48.7	49.5
Female	51.4	51.7	52.6	48.8	48.5	47.4	51.3	50.5
Deprivation								
Deprived	34.6	39.0	10.2	30.9	43.2	61.1	29.2	22.4
4	22.0	14.4	26.9	36.3	26.3	25.8	31.2	30.5
3	17.5	20.0	31.9	29.3	13.1	9.8	21.5	17.5
2	13.9	14.9	22.1	2.3	8.2	2.2	11.2	18.0
Affluent	12.0	11.8	8.9	1.2	9.1	1.0	6.8	11.6
Cause of Death								
Cancer	27.7	26.2	27.8	28.2	29.1	27.5	26.9	26.3
Cardio-vascular	28.6	30.6	31.1	27.2	27.8	28.7	29.8	29.8
Other	29.6	28.7	28.4	28.9	30.6	30.8	29.2	28.2
Respiratory	14.1	14.5	12.7	15.6	12.4	13.0	14.1	15.7
Place of Death								
Elsewhere	1.9	2.5	1.8	1.3	2.6	2.5	1.7	1.9
Hospital	56.7	50.1	50.6	55.1	56.1	61.9	62.8	58.3
Hospice	5.1	3.3	5.5	6.7	8.9	6.6	4.8	5.9
Nursing Homes	9.5	16.1	10.0	9.0	4.8	5.3	7.3	11.5
Old People's Homes	5.8	8.2	11.3	7.4	5.5	2.9	4.7	3.8
Own Residence	21.0	19.9	20.7	20.5	22.1	20.7	18.8	18.6
All Deaths	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0



Death profile, PCTs & England 2010 Percentage of deaths (continued)

ONS Group (e.g. PCT)	Mining and Manufacturing	County Durham	Prospering UK	Bath and North East Somerset	East Sussex Downs and Weald	Oxfordshire	ENGLAND
Age							
0-44	3.9	3.7	3.5	2.8	2.7	3.9	4.1
45-64	14.0	14.1	11.8	9.9	9.2	11.3	13.0
65-74	17.8	17.5	15.2	14.3	12.9	15.1	16.0
75-84	31.5	32.6	30.1	28.7	30.2	28.7	30.0
85+	32.9	32.1	39.4	44.3	45.0	41.0	36.8
Gender							
Male	48.4	48.3	47.8	47.5	46.4	47.1	48.2
Female	51.6	51.7	52.2	52.5	53.6	52.9	51.8
Deprivation							
Deprived	28.9	27.1	7.5	3.7	4.3	2.3	19.5
4	25.1	35.5	18.5	16.6	21.6	11.7	21.8
3	19.0	20.7	23.8	19.5	28.7	19.6	21.8
2	15.7	7.1	26.9	30.9	29.1	30.9	20.5
Affluent	11.2	9.6	23.3	29.2	16.3	35.6	16.4
Cause of Death							
Cancer	29.0	28.4	28.1	27.8	27.4	29.8	28.1
Cardio-vascular	28.0	27.7	29.3	29.1	33.9	26.1	29.1
Other	28.6	29.3	29.2	32.2	26.3	30.8	29.2
Respiratory	14.5	14.7	13.3	10.6	12.4	13.3	13.6
Place of Death							
Elsewhere	1.9	2.1	1.9	1.9	2.1	1.8	1.9
Hospital	57.0	54.8	53.2	46.4	51.2	51.4	55.0
Hospice	4.6	3.2	5.5	2.9	4.9	6.9	5.3
Nursing Homes	9.0	10.5	9.7	18.1	16.3	11.0	9.3
Old People's Homes	6.1	6.3	8.8	8.4	7.1	7.1	7.6
Own Residence	21.2	23.1	20.9	22.3	18.4	21.9	20.9
All Deaths	100.0	100.0	100.0	100.0	100.0	100.0	100.0



General Practice Data, 2010

ONS Group (e.g. PCT)	GPs (FTE)*	GP Registered population	Average number of people per GP FTE	Number of deaths	Average number of deaths per GP FTE
Cities and Services	7,395	11,971,014	1,619	93,438	13
Bradford and Airedale	394	547,506	1,388	4,293	11
Coastal and Countryside	2,478	3,421,435	1,381	37,640	15
Blackpool	95	152,561	1,605	1,880	20
London Centre	1,226	1,718,256	1,402	7,631	6
London Cosmopolitan	1,538	2,589,874	1,684	11,368	7
London Suburbs	1,707	2,959,467	1,734	17,911	10
Croydon	245	382,106	1,560	2,496	10
Mining and Manufacturing	5,278	7,969,102	1,510	76,276	14
County Durham	403	531,525	1,320	5,109	13
Prospering UK	15,620	24,390,042	1,561	216,752	14
Bath and North East Somerset	132	194,429	1,470	1,669	13
East Sussex Downs and Weald	240	346,911	1,443	4,069	17
Oxfordshire	430	668,920	1,557	4,917	11
England	35,243	55,019,190	1,561	461,016	13

*FTE – GP full time equivalent. Where 1 = 37.5 hours

Source: NHS Information centre:

<http://www.ic.nhs.uk/statistics-and-data-collections/workforce/nhs-staff-numbers/nhs-staff-2000-2010-general-practice>



Population profile, PCTs & England 2010 Number of residents

PCT	Bath and North East Somerset	Blackpool	Bradford and Airedale	County Durham	Croydon	East Sussex Downs and Weald	Oxfordshire	ENGLAND
Age								
0-44	103,748	75,356	327,282	279,327	214,327	162,104	371,347	30,388,365
45-64	44,336	37,484	116,409	140,421	86,049	95,038	155,392	13,239,361
65-74	15,539	14,268	35,165	49,544	23,589	38,114	50,078	4,486,953
75-84	11,183	9,161	24,285	30,751	15,170	27,671	32,866	2,921,530
85+	4,898	3,705	9,477	10,761	6,427	13,221	14,415	1,197,836
Gender								
Male	88,920	69,002	253,293	250,849	169,383	161,059	308,992	25,757,629
Female	90,784	70,972	259,325	259,955	176,179	175,119	315,106	26,476,416
Deprivation								
Deprived	7,319	47,702	216,241	128,942	76,127	20,713	17,772	10,468,152
4	27,415	47,963	71,723	159,801	114,315	71,197	68,911	10,501,335
3	33,643	39,448	90,921	104,064	66,929	84,041	111,263	10,467,158
2	51,753	3,203	72,464	43,091	48,377	98,718	177,139	10,423,910
Affluent	59,574	1,658	61,269	74,906	39,814	61,509	249,013	10,373,490
Total Population	179,704	139,974	512,618	510,804	345,562	336,178	624,098	52,234,045



Population profile, PCTs & England 2010 Proportion of residents

ONS Group (e.g. PCT)	Cities and Services	Bradford and Airedale	Coastal and Countryside	Blackpool	London Centre	London Cosmopolitan	London Suburbs	Croydon
Age								
0-44	63.2	63.8	49.3	53.8	72.2	71.3	65.0	62.0
45-64	22.7	22.7	28.3	26.8	18.2	19.5	22.7	24.9
65-74	7.2	6.9	11.5	10.2	4.9	4.9	6.3	6.8
75-84	4.9	4.7	7.5	6.5	3.3	3.2	4.2	4.4
85+	2.0	1.8	3.3	2.6	1.4	1.2	1.8	1.9
Gender								
Male	49.5	49.4	48.8	49.3	49.9	50.6	49.9	49.0
Female	50.5	50.6	51.2	50.7	50.1	49.4	50.1	51.0
Deprivation								
Deprived	33.0	42.2	10.6	34.1	39.2	60.7	30.0	22.0
4	20.2	14.0	24.7	34.3	24.2	26.0	32.2	33.1
3	17.4	17.7	31.0	28.2	14.7	9.5	20.8	19.4
2	14.7	14.1	23.0	2.3	9.6	2.2	10.3	14.0
Affluent	14.7	12.0	10.7	1.2	12.3	1.5	6.7	11.5
Total Population	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0



Population profile, PCTs & England 2010 Proportion of residents (continued)

ONS Group (e.g. PCT)	Mining and Manufacturing	County Durham	Prospering UK	Bath and North East Somerset	East Sussex Downs and Weald	Oxfordshire	ENGLAND
Age							
0-44	55.5	54.7	55.1	57.7	48.2	59.5	58.2
45-64	27.0	27.5	26.9	24.7	28.3	24.9	25.3
65-74	9.3	9.7	9.4	8.6	11.3	8.0	8.6
75-84	5.9	6.0	6.1	6.2	8.2	5.3	5.6
85+	2.2	2.1	2.5	2.7	3.9	2.3	2.3
Gender							
Male	49.0	49.1	49.2	49.5	47.9	49.5	49.3
Female	51.0	50.9	50.8	50.5	52.1	50.5	50.7
Deprivation							
Deprived	26.2	25.2	7.3	4.1	6.2	2.8	20.0
4	22.6	31.3	16.4	15.3	21.2	11.0	20.1
3	18.5	20.4	21.4	18.7	25.0	17.8	20.0
2	17.3	8.4	26.2	28.8	29.4	28.4	20.0
Affluent	15.3	14.7	28.7	33.2	18.3	39.9	19.9
Total Population	100.0	100.0	100.0	100.0	100.0	100.0	100.0



Appendix D

Profiles for each of the PCT AREAS

1. Croydon

2. Blackpool

3. Bath and North East Somerset

4. East Sussex Downs and Weald

5. Bradford and Airedale

6. County Durham

7. Oxfordshire

(Note: Where case studies and examples have been provided these have not been edited but kept in their original style and format within the profile)



1. Profile for the Croydon PCT Area

The following ranges are based on publically available ONS Place of Death Indicators released for 2008/09 Q3 to Q2 compared with 2009/10 Q3 to Q2 and are expressed as deaths at home (defined as home, care homes (NHS and non-NHS)), and religious establishments as a percentage of overall deaths:

	08/09	09/10	+/-
Croydon – London Suburbs	28.9%	34.5%	5.6%
Blackpool – Coastal and Country	31.9%	37.4%	5.5%
Bath and North East Somerset (BANES) – Prospering UK	44.5%	47.5%	3.0%
East Sussex Downs and Weald – Prospering UK	43.4%	45.9%	2.5%
Bradford and Airedale – Cities and Services	47.1%	47.3%	0.3%
County Durham – Mining and Manufacturing	40.8%	40.9%	0.1%
Oxfordshire – Prospering UK	42.1%	41.9%	-0.2%

Croydon at a glance

The health of people in Croydon is mixed compared to the England average. Deprivation is lower than average, however 21,565 children live in poverty. Life expectancy for both men and women is higher than the England average.

Life expectancy is 9.5 years lower for men and 5.2 years lower for women in the most deprived areas of Croydon than in the least deprived areas (based on the Slope Index of Inequality published on 5th January 2011).

Over the last 10 years, all-cause mortality rates have fallen. Early death rates from cancer and from heart disease and stroke have fallen.

About 22.1% of Year 6 children are classified as obese. 55.2% of pupils spend at least three hours each week on school sport. Levels of teenage pregnancy are worse than the England average.

An estimated 19.7% of adults smoke and 24.3% are obese. There were 6,071 hospital stays for alcohol related harm in 2009/10 and there are 408 deaths from smoking each year. Priorities in Croydon include early intervention, especially for children, promoting independent living and mental health. For more information see www.croydon.nhs.uk

Source: www.healthprofiles.info



Basic Information:

1. Information held on Preferred Place of Death	Yes – as part of Local Enhancement Scheme (LES) for primary care – see further details in 'Progress to Date' section.
2. Triggers including electronic information systems	'co-ordinate my care' gradually being tested; MDT within primary care have reviewed older frail patients and those in care homes to consider if they would be appropriate for GSF- this has resulted in an increase in non-cancer patients on end of life care registers from 1/3 to 2/3. CQUIN in secondary care is aimed at supporting advance care planning with patients with long term conditions.
3. Services in the area	Croydon University Hospital and St Christopher's Hospice provide a unified service. DNs service is 24/7 but demands are high on the service. Palliative care provided in care homes supported by St. Christopher's. Crossroads Carer Support provides personal care to enable carers to have respite and shown that it has saved more expensive interventions.
4. MDT's/ Communications	Monthly /MDT meetings co-ordinated by primary care; Further work on going with secondary care to support advance care planning with patients who have long term conditions such as COPD and Heart Failure who have unpredictable disease trajectories.
5. Protocols and Tools	GSF, LCP widely used across services. Concept of PPC also used. St Christopher's Blue Book to support ACP No cross agency agreement on DNACPR yet.
6. Joint working	Social care (reablement) investment plan has been agreed to include support for personal care and carer respite at end of life. Croydon is one of five PCTs with an SLA with St. Christopher's – St Christopher's specialist nurse seconded in to GSF role.
7. Suggested factors that can make a difference:	<ul style="list-style-type: none"> ● Good commissioning support with engaged/informed commissioner who knows the subject area and care settings – approach in Croydon as been 'invest to save' by an enlightened commissioner e.g. care home work with St Christopher's initially funded from charitable monies and the PCT recognised the impact and took over the funding ● Audit the whole system and get agreement of what the priorities are ● Start with getting Primary Care right ● Have facilitators on the ground to inform why and how plus practical support – GP Clinical Champion to bend ears and influence other GPs, GSF and LCP facilitators help and buddying arrangement for learning from those who have made things work – get people working as a wider 'team' e.g. dementia facilitator ● LES and CQUINs incentives – feedback has shown 300 unnecessary admissions were avoided and contributes to QIPP (acknowledges that it may be easier given only one main acute provider and one main hospice) ● Succession planning for the future – benefit of having the GP Clinical Champion Camilla Chamber, who has established the correct connections – need to work with practice managers ● Secondary care to support primary care with specialist knowledge to raise confidence to move from interventions to palliative care where needed ● Flexibility to purchase premium 'gold standard' beds in nursing homes and use more funds to support personal care.



Further Information (FIs):

Progress to date – provided by Jacqueline Goodchild – PCT lead

The work to improve care at end of life commenced in Croydon with the End of Life Strategy Group (made up of Commissioners and informed by providers in NHS and the independent sector) completing a baseline review of End of Life care services in Croydon in March 2008.

This baseline review highlighted that the PCT has many strengths to build on when developing EoLC services, including:

- a 24 hour District Nursing Service
- a strong partnership with NHS, Social Care and independent sector providers reflected in the membership of the End of Life Strategy Group
- a commitment across the Borough to improve care at the end of life, through training and implementation of best practice models
- passionate specialist care teams
- support for carers that is continued after death

However a provisional gap analysis was undertaken highlighting that:

- Implementation of best practice models needed additional resourcing to improve and sustain take up
- Need to ensure equity of access to support regardless of diagnosis
- Emphasis should be on determining patients preferred place of care
- The balance of investment in end of life care needed to be re-profiled to support people to die in the place of their choice

A small project was established with our local Hospice, St. Christopher's, to facilitate the implementation of Gold Standards Framework (GSF) in primary care, but a review of impact in 2009 established that there had been limited engagement and this was demonstrated by:

- Inconsistent establishment of palliative care registers in general practice
- Patients on register predominately having a diagnosis of cancer
- A lack of regular reviews of patients' needs

As a result it was agreed to adopt a more robust approach increasing the amount of facilitation time providing a project support structure and identifying a GP clinical champion.

After 6 months the project group recognised the need to support practices in the implementation of best practice and a Local Enhanced Service (LES) was developed with GPs to enable them to assist patients to achieve their preferred place of care and reduce unnecessary hospital admissions. This was well supported locally with 95% of the registered population of Croydon being covered by practices signed up to the LES.



Practices were also asked to complete an after death analysis (ADA) form for each death to a patient registered with the practice. This information enabled us to monitor how well practices were implementing best practice and whether patients were able to achieve their preferred place of care. We found that just over a third of patients that died had their preferred place of care recorded, with 74% of patients being able to achieve this.

This demonstrated that where patient's wishes are known services can in the main be delivered to support them.

We revised the LES in 2010/11 to:

- embed implementation of best practice
- support training particularly the use of e-learning modules
- include completion of ADAs to enable us to monitor the impact of the approach

Achievements in 2010/11

- over 1800 ADAs have been submitted in total so far (this represents 2/3rds of expected deaths in Croydon)
- for 37% of deaths the patients were on a Palliative care register and 2/3rds of those patients had a non-cancer diagnosis
- 32% of patients that died achieved their preferred place of care (PPC)
- Patients were twice as likely to achieve their PPC if they were on a palliative care register.
- So far this year to over 300 hospital admissions have been prevented as GPs have ensured -
 - Co-ordination of care with District Nursing, specialist palliative care out of hours provision and care home staff
 - Advance discussions with relatives and patient about preferences are undertaken and recorded
 - Provision of appropriate anticipatory medications.

And importantly feedback from practices and practitioners is that the process of review has been positive as it provides an opportunity to develop strong multi-disciplinary relationships with the patient at the centre.

This is what one GP said-

"forward planning has helped our families and patients. We can give them advice about benefits, let them know the options for care and avoid unnecessary admissions to hospital, non-cancer patients as well, giving a peaceful death where they want to be... The Framework ensures that everyone gets the same level of care. The more you do it the easier it becomes. It's speaking to patients as you would want your own relatives spoken to."

We continue to develop our approach and have recently put on a Protected Learning session for GPs to provide support for Advance Care Planning was well attended and well received.

Challenges for next year include:

- Working with Residential Homes to support best practice at end of life
- Improving communications between different providers of care
- An emphasis on Advance care planning encouraging patients to think about their preferences at end of life and recording them so that they have the best chance of having a good death.



FI 1 – Case Study from St Christopher's Hospice – Developing Care Homes

Croydon PCT funds 1FTE end of life care facilitator post (job shared by 2 people) to develop end of life care in care homes.

Croydon PCT has a population of 345,000 and is one of five the PCTs covered by The Care Homes Project Team at St Christopher's Hospice. Croydon PCT now funds 1FTE end of life care facilitator to work to change the culture and practice of end of life care in Croydon Nursing Care Homes. This funding has come as a result of being able to evidence improved statistics on residents being able to stay in the NCH to die.

Various end of life care tools recommended by the Department of Health are used to bring about change in NCHs; these include: the Gold Standard Framework for Care Homes (GSFCH) to introduce a number of organizational systems, improved coordination and communication with GPs and families; an Integrated Care Pathway (ICP) to help guide the care in the last days of life; and assessment tools for pain & depression. The number of NCHs undertaking the programme at any one time is carefully monitored so that the facilitator has time to give 'high' facilitation; this is worked out as two NCHs per 0.2FTE. All NCHs pay to undertake the programme.

To date all 25 nursing care homes (NCHs) in Croydon have been or currently undertaking the GSFCH programme. Nurse managers are encouraged to go for GSFCH accreditation (generally after 18 months) once they feel the programme is embedded. It is encouraging that, within the last three years, 13 NCHs are accredited with the majority (85%) getting either 'beacon' or a 'commendation' status.

All NCHs complete a monthly audit on deaths. This includes collecting data on: age, length of stay, co-morbidities documentation re ACP, DNACPR & ICP as well as where the death occurred. Last year 76% of residents were able to die in the NCHs compared to 55% in 2008 when the project commenced. The ICP was completed in 60% of all deaths.

Hospice at Home into Care Homes:

A charitable donation from Croydon in Need has made it possible for us to employ a nurse practitioner in palliative care (10hrs/week) to work alongside those NCHs that are struggling to complete the GSFCH programme. This is generally because of disrupted leadership causing a high turnover of staff. The nurse practitioner works alongside staff caring for residents who are at the very end of life; she will also take on training within the home as appropriate. She is currently working across two NCHs.

Sustainability Initiative:

Sustainability of the above work is not without cost. The sustainability initiative (now part funded by the NCHs themselves) is well established across Croydon PCT. The 25 NCHs are divided geographically into 3 cluster groups. Each cluster group has three levels:

- **All new staff** (including domestics, gardeners etc) attend an **INDUCTION DAY** within 6 months of starting at the nursing home. These are held every 6 months.
- **Regular care staff and nurses** who have worked at the NCH for 12 months or more attend 4 days training (Macmillan Foundations in Palliative Care for Care Homes) over the year.
- **Clinical leads/nurse managers** attend action learning set every 2 months

Goals and objectives for 2011/2012:

Now that the NCHs have nearly all completed the GSFCH/ICP programme our attention turns to the residential care homes (RCHs). A new programme based on the DH (2010) 'Steps to success in end of life care for care homes' is being piloted in 4 RCHs. The importance of this programme is to galvanise primary care support especially with district nursing.

Jo Hockley -Nurse Consultant, Care Home Project & Research Team, St Christopher's



FI 2 – Croydon's End of Life Care Training Approach – A response to CQUIN

NHS Croydon is currently targeting the 'End of Life Care' eLearning programme to 152 staff who directly work in the delivery of end of life care and as a direct response to Commissioning for Quality and Innovation (CQUIN) payment framework. The CQUIN payment framework makes a proportion of providers' income conditional on quality and innovation. Its aim is to support the vision set out in high quality care for all of an NHS where quality is the organising principle.

NHS Croydon has approximately 800 staff providing health care to a diverse community of approximately 350,000 residents. As a Trust they have been actively using eLearning through the NLMS since April 2010 and have been accessing the End of Life Care courses since July 2010.

Prior to the implementation of NLMS (OLM eLearning), the Trust had a limited but developing eLearning culture. However the links with CQUIN payment framework provided a direct driver towards eLearning and the End of Life Care programme. As a Trust it was decided that their local strategy would be to implement the delivery of the programme through the creation of 'End of Life Care Workshops'. These workshops were for an entire day and were arranged as protected time so not to impact on patients. The sessions were facilitated in an IT training room and delegates accessed the relevant eLearning packages throughout the session. A selection of staff with both clinical and non-clinical backgrounds were also specifically trained in the role of super users to be on hand to support users and answer questions on the day. The delivery of the programme was presented in line with the eLearning package and classroom based discussion; the feedback received has been extremely positive and staff that were lacking confidence with computers have excelled. All staff can further develop their knowledge with over 160 hours of End of Life Care eLearning available on the NLMS.

"Staff who have attended so far are pleased with this method as they say the reflective questions enables in-depth discussions as well as discussions of work base issues and reflection on clinical practice. Staff who have attended also commented that working in groups facilitates diverse perspectives which they found useful."

Sarah Keene, Clinical Nurse Trainer, NHS Croydon

"A good refresher after my work base project and degree in end of life care which will enable a good reflection on my practice and communication skills, excellent session.... have enjoyed the eLearning content and will practice what I have learned when visiting palliative patients."

learners comments, Croydon PCT NHS Croydon

Next Steps

NHS Croydon are planning to focus training on enhancing communications, assessment and advance care planning by utilising the End of Life Care material. This will be a joint initiative with St Christopher's hospice which actively promotes end of life care through education, training, research and clinical practice. This training will be conducted through the involvement of case studies and specific scenarios which will enable the link between theory and clinical practice. Training will also be centred around the awareness of dementia which is currently a key feature on the health care agenda; this is due to the consequent link in certain individuals who experience dementia with related end of life care issues. The aim will be to target 150 staff members ranging from bands 3-8 to ensure that all staff that has contact with end of life care patients in the community will be trained appropriately and to the same level. Proposals have also been agreed to extend the training to the attention of the council ran homes which has approximately 150 patients who are suffering with dementia or are physically frail in order to inform and improve care provision for these group of individuals. These staff will access the same learning through the e-LfH Learning Management System (LMS). They are also planning to continue embedding the eLearning end of life care topics and enabling a re-visitation as well as refreshers for staff to continue their learning and development.



NHS Croydon Top eLearning End of Life Care Tips

- Individuals who attended the course have enjoyed the content and found it very relevant. The reflective boxes do offer opportunities for discussion and linkage to clinical practice.
- Minimising attendance numbers and only having 8-10 learners per session were evaluated as excellent, as it enabled some form of safety with regards to the sharing experiences and providing answers to question discussions.
- Enabling short breaks during the session were deemed extremely helpful and also allowed individuals to reflect on the materials as well as have a break from the screen.
- Mixing the staff bands with the sessions did not appear to impact negatively on learning as junior staff were also able to add value and contribute during discussions as well as share experiences.
- Staff reflecting on clinical experiences as well as hearing alternative perspective appeared to be helpful to attendees.

We would like to thank NHS Croydon in contributing to the article if you require any further information on NHS Croydon's approach to end of life care eLearning training through the NLMS please contact:

Cath Burgess

Workforce Development Advisor

Cath.burgess@croydonpct.nhs.uk

Source: NEoLCP ESR Report Case Study

Contributors

The following people gave up time to contribute to this work:

Jacqueline Goodchild	Senior Commissioning Manager Older People and Long Term Conditions, Croydon Borough Team
Rob George	SHA EoLC Lead
Anna Butt	End of Life Care Facilitator, Croydon Residential Homes, St Christopher's Hospice
Jo Hockley	Nurse Consultant, Care Home Project Team, St Christopher's Hospice.
Penny Hansford	St Christopher's Hospice



2. Profile for the Blackpool PCT Area

The following ranges are based on publically available ONS Place of Death Indicators released for 2008/09 Q3 to Q2 compared with 2009/10 Q3 to Q2 and are expressed as deaths at home (defined as home, care homes (NHS and non-NHS)), and religious establishments as a percentage of overall deaths:

	08/09	09/10	+/-
Croydon – London Suburbs	28.9%	34.5%	5.6%
Blackpool – Coastal and Country	31.9%	37.4%	5.5%
Bath and North East Somerset (BANES) – Prospering UK	44.5%	47.5%	3.0%
East Sussex Downs and Weald – Prospering UK	43.4%	45.9%	2.5%
Bradford and Airedale – Cities and Services	47.1%	47.3%	0.3%
County Durham – Mining and Manufacturing	40.8%	40.9%	0.1%
Oxfordshire – Prospering UK	42.1%	41.9%	-0.2%

Blackpool at a glance

The health of people in Blackpool is generally worse than the England average. Deprivation is higher than average and 9,070 children live in poverty. Life expectancy for both men and women is lower than the England average.

Life expectancy is 13.3 years lower for men and 8.3 years lower for women in the most deprived areas of Blackpool than in the least deprived areas (based on the Slope Index of Inequality published on 5th January 2011).

Over the last 10 years, all cause mortality rates have fallen. Early death rates from cancer and from heart disease and stroke have fallen but remain worse than the England average.

About 18.8% of Year 6 children are classified as obese. 54.6% of pupils spend at least three hours each week on school sport. Levels of teenage pregnancy, GCSE attainment and tooth decay in children are worse than the England average.

Estimated levels of adult 'healthy eating' and smoking are worse than the England average. Rates of smoking related deaths and hospital stays for alcohol related harm are higher than average.

Priorities in Blackpool include alcohol and substance misuse, smoking and obesity. For more information see www.blackpool.nhs.uk

Source: www.healthprofiles.info



Basic Information:

8. Information held on Preferred Place of Death	<p>Annual '60 Death Audit' looks at a snapshot of 60 deaths within one calendar month and looks to see if deaths in hospital were appropriate or not and also if the patient had chosen PPD as within hospital.</p> <p>On-going audit of LCP monitors if patients have an ACP if they died in Hospital.</p> <p>Trinity routinely collect preferred place of death information on all patients referred to the service. Where some part of the hospice service is or has been involved just over 70% of patients achieve their preferred place of death.</p>
9. Triggers including electronic information systems	<p>The Acute Trust cannot access locality registers which can cause problems if patient admitted through A&E. However all patients involved with Trinity are put on MAXIMS as an alert for A & E staff.</p> <p>Utilising locally adapted version of the North West EoLC model to help clinicians identify where patients are on the pathway.</p> <p>Other triggers can be OOH forms, GSF surprise question, and in primary and community care the on-going collaborative work across primary care, secondary care, OOH and the voluntary sector (including Trinity).</p> <p>Working with the out of hours cooperative which provides cover in the locality so that GPs can send OOH forms via ADAstra web and can update these directly.</p> <p>Rolled out across all of Fylde and Wyre and part of Blackpool.</p>
10. Services in the area	<p>Blackpool Teaching Hospitals (BTH) NHS FT – covers 2 PCT areas.</p> <p>Trinity Hospice – covers 2 PCT areas SPC Team – 1 WTE Medical Director/Hospice Consultant in Palliative Medicine, 1 WTE Hospital Consultant in Palliative Medicine who works with 4 WTE Hospital CNS based within BTH but employed and funded by Trinity.</p> <p>Trinity's Medical Director runs the specialist in-patient unit and day hospice Also 0.6 WTE Community Consultant employed by Trinity with 8 WTE Trinity based CNS who work across Blackpool, Fylde and Wyre (approx. 3 WTE CNS for Blackpool).</p> <p>DNs do not provide 24 hr service but 24hr advice helpline available via Trinity as well as 24 hr social care support available OOH provided across all settings – Nurses who are part of the OOH service do not go out to those who are dying until they have undertaken some Macmillan training and feel confident to do so.</p> <p>Marie Curie Services at home Established Rapid Discharge process (within 4 hours if the patient has days to live, 24 hours if less than 4 weeks to live) for dying patients that links with the hospital discharge team and continuing care, and Trinity community support via CNS team.</p>
11. MDT's/ Communications	<p>Weekly SPC MDT that includes hospital, primary care and hospice teams – led by Trinity Bimonthly training sessions held with link professionals from all areas of the health and social economy</p>
12. Protocols and Tools	<p>LCP is well established – use accounts for approximately 30% of all deaths within BTH On-going implementation of ACP training across organisations.</p> <p>Health economy wide DNAR policy Care after Death protocols in place GSF (Care Homes) accreditation process Blackpool Model for all Care Homes not undertaking GSF.</p> <p>Network pain & symptom control guidance has been summarised into an A4 palliative care prescribing card for GPs (which has been included in the EoL Resource Pack) – each GP has an individual copy available on the Trinity website.</p> <p>The End of Life Resource downloaded from the Trinity website.</p> <p>Just in Case' policy and guidance.</p> <p>Working group on joint syringe driver policy Follow network guidelines on symptom control.</p>



13. Joint working

Joint EoLC strategy with social care.

Joint working in the BTH on continuing care but do not have identified social care staff within the Trust – close liaison and referral systems in place within BTH to both Blackpool and Lancashire Social Services.

Trinity Hospice has a dedicated social worker from Blackpool Social Services who provides a service for both Blackpool and Lancashire patients.

Have a end of life care board chaired by a community consultant which works across the Blackpool, Fylde and Wyre health and social care economy to unify care – three work streams – education and training, quality of care and co-ordination and audit of care.

Strong links with Churches through Stepping Stones bereavement groups.

Strong links with Ripples a Community interest company set up by Trinity to build resilience both with children and adults through group work and one to one sessions.

14. Suggested factors that can make a difference:

- 24/7 Care Provision at Home
- Electronic locality register systems accessible to all eolc services
- Early recognition of the dying phase by clinicians
- Lead coordinator to implement GSF – within the care homes the value is not only in using GSF but having the support from the coordinator
- Development of key worker to pass the baton to across settings
- Social marketing – raising societal awareness regarding death and dying
- Rolling programme of end of life education – focus on mandatory training sometimes means it is not given the priority rating it needs
- Hospice at Home service
- Need consistent policies e.g. DNACPR, common paperwork etc.
- Must have honest communication with patients and families – often panic sets in when deterioration happens and can cause unnecessary admissions to acute
- The trigger happens in different places but must be where the patient has a relationship where they feel comfortable to discuss the issues. They will give clues and prompts of where and with whom they want but it is important that they have information available to know they can choose who to have the conversation with.
- Adequate funding for 7 day a week working of the Trinity based CNS team and to enable admissions to the hospice at weekends
- Central referral hub for end of life care



Further Information (FIs) and synthesis of discussions with a range of contributors

All contributors highlighted the strength of collaborative working across the PCT, Blackpool Teaching Hospitals and Trinity Hospice. Two Macmillan GP Facilitators are also in post.

A combined locality MDT is in place so communication is good and notes/information are shared which helps negate the effect of electronic systems not being joined up.

The following briefly illustrates some of the work undertaken and in progress and three examples of patient experiences provided by the PCT across care services can be found within FI 1 Case Study:

EoLC Team at the NHS Blackpool PCT

The team comprises of a clinical lead, whose role is around service development and training. Training is delivered to any health, social care, voluntary group, patient group who require training. She also facilitates training through different groups, e.g., Motor neurone training for health and social care staff, delivered by the MND Association or bereavement support and listening skills delivered by the Trinity Hospice.

Also in the team is a Care Homes Facilitator whose role is to support development within Care Homes. Gold Standards Framework is offered and for those not undertaking GSF, an educational model has been developed locally, which is adapted to meet the needs of individual homes and clients (See FI 2). This includes supported housing for patients with learning disabilities. There are 83 care homes in Blackpool. There are two further staff supporting the care homes. Basic nursing care training is also available to the care homes. All training is delivered based on the North West adapted model, which is also attached (See FI 3).

Blackpool Teaching Hospitals NHS FT

Within BTH there is a clinical lead and a project lead for EOLC – EOL project team comprises of lead cancer nurse, eol project coordinator, palliative medicine consultant, CNS Palliative Care, chaplaincy, hospital discharge team and divisional representatives. Work within the Trust includes communication skills training using Sage and Thyme as well as ACST. A modular training programme for eolc which includes communication skills, LCP, ACP (and the NW EoL model), Symptom Control as well as a three day training programme regarding bereavement that staff can choose to do one, two or three days. This is being rolled out after being piloted on two acute medical and respiratory wards. The Trust does have access to e-ELCA although this is not currently in widespread use. In addition the Trust has undertaken or is in the process of:

- Participated in GSF for acute hospitals project for haematology OPD
- Undertakes the 60 deaths audit annually
- Liaison with community care providers (GPs, DNs, Care Homes, OOH, Trinity) when a patient is being discharged rapidly at the end of life
- Develop posters in the Trust to try and raise awareness that patients have a choice in where they are cared for in end of life combining PPC and NW EoL Model alongside local information

Trinity Hospice

The Hospice's CNSs as well as DNs provide support to care homes. This includes holding four syringe drivers at the hospice for which care home staff have access and have been trained to use them. This is seen as one of the ways to break down barriers.

The Network has paid for a training programme to build confidence around end of life care for social care and care home staff without qualifications. The programme is delivered over a 4 week period and has received very positive feedback (See FI 4):



They have also held three 1 day events to encourage health and social care professionals to come together and discuss the importance of advance care planning within end of life care. This included those involved in direct care as well as those who engage with the pathway such as clergy, solicitors etc. Also on one of the days public and voluntary organisations were encouraged to attend. Other work has also been undertaken with community based pharmacists and others around building skills, knowledge and confidence (especially around communication skills and the benefits of ACP).

An EoLC resource pack is on the website which details the resources available and also eolc tools and guidance on JIC boxes. (See FI 5) This was developed in partnership with the community and acute teams.

As mentioned in the Basic Information section the SPC team within BHT are employed by the Hospice and also provide in reach and outreach services to the acute and others. A social worker at Trinity works across the area which facilitates transferring patients' home from the hospice.

The hospice are planning on setting up a Hospice at Home service which will include practical hands on care for evening, weekends and night care as well as respite care. This was developed in partnership with PCTs. The Hospice in partnership with the Dying Matters Coalition held a GP training workshop as part of the national work to help increase GP's confidence in having conversations on end of life with patients, families and carers.

FI 1 – Case Study – Examples of Patient Experiences

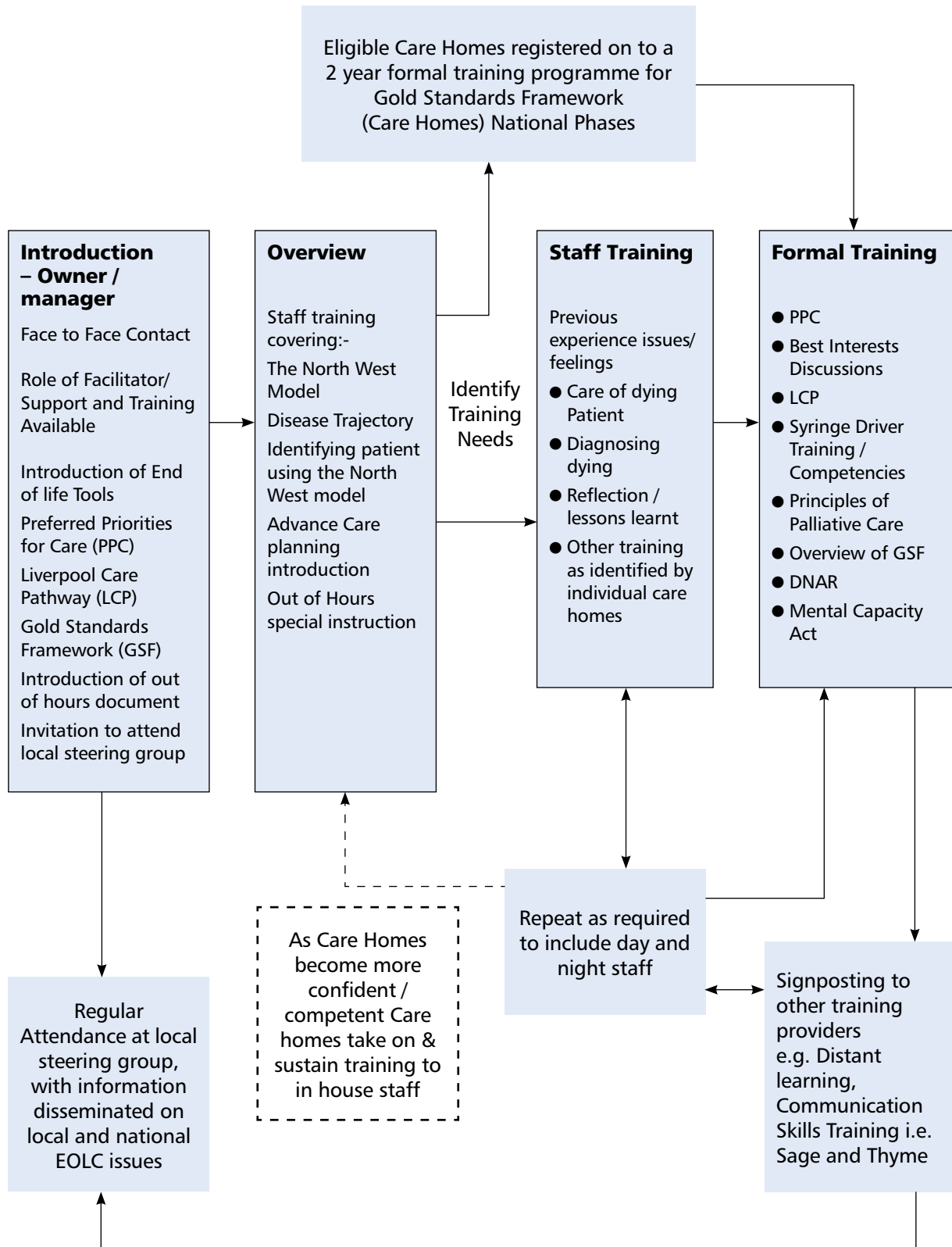
Patient A had carcinoma with liver metastases. She lived with her husband who was the main carer. She received visits from District nurses (DN) and was known to the clinical nurse specialist (CNS) from Trinity Hospice. On a Monday morning the husband phoned the CNS very distressed stating that he could no longer look after her and that unless she was moved that day then he would take her to A&E. The CNS contacted the DN team and the continuing health care team. Following discussion with patient A and her family it was agreed to transfer her to a nursing home via a fast track. A bed was available in a Gold Standards Framework Nursing home, the GP was in agreement and the lady was transferred via a private ambulance to the nursing home later that day. She died 3 days later in the nursing home with her husband. He stated that when she was in the Nursing home he could be a husband and not a carer.

Patient B had dementia and had lived for many years in a Nursing home; the home had recently commenced the GSF training programme. A best interest decision for end of life care had been completed for patient B and the out of hours GP services had been informed. Her grandson worked for the company as a handyman and had been involved in GSF meetings. Patient B was admitted to hospital for investigations, whilst in hospital she deteriorated and identified as in the dying phase. Following discussions with the family they requested she return to the nursing home as per her best interest discussions of preferred place of care at end of life. Patient fast tracked back to nursing home on the Liverpool Care Pathway later that day. Patient died peacefully in nursing home two days later, surrounded by family in familiar surroundings.

Patient C lived alone at home, supported by a close friend; she had a history of heart failure and was under the care of the community matron. Previous offers of social care help had been declined. The community matron identified that the patient was dying. The patient had stated that she wanted to remain at home. Carer struggling to manage care required. The community matron liaised with GP, district nurses and continuing care team. Fast track tool completed, care commenced with two carers four times a day, carers had previously undergone training with the end of life team and hospice. The patient was supported from the district nurses and community matron. She died at home the following day.

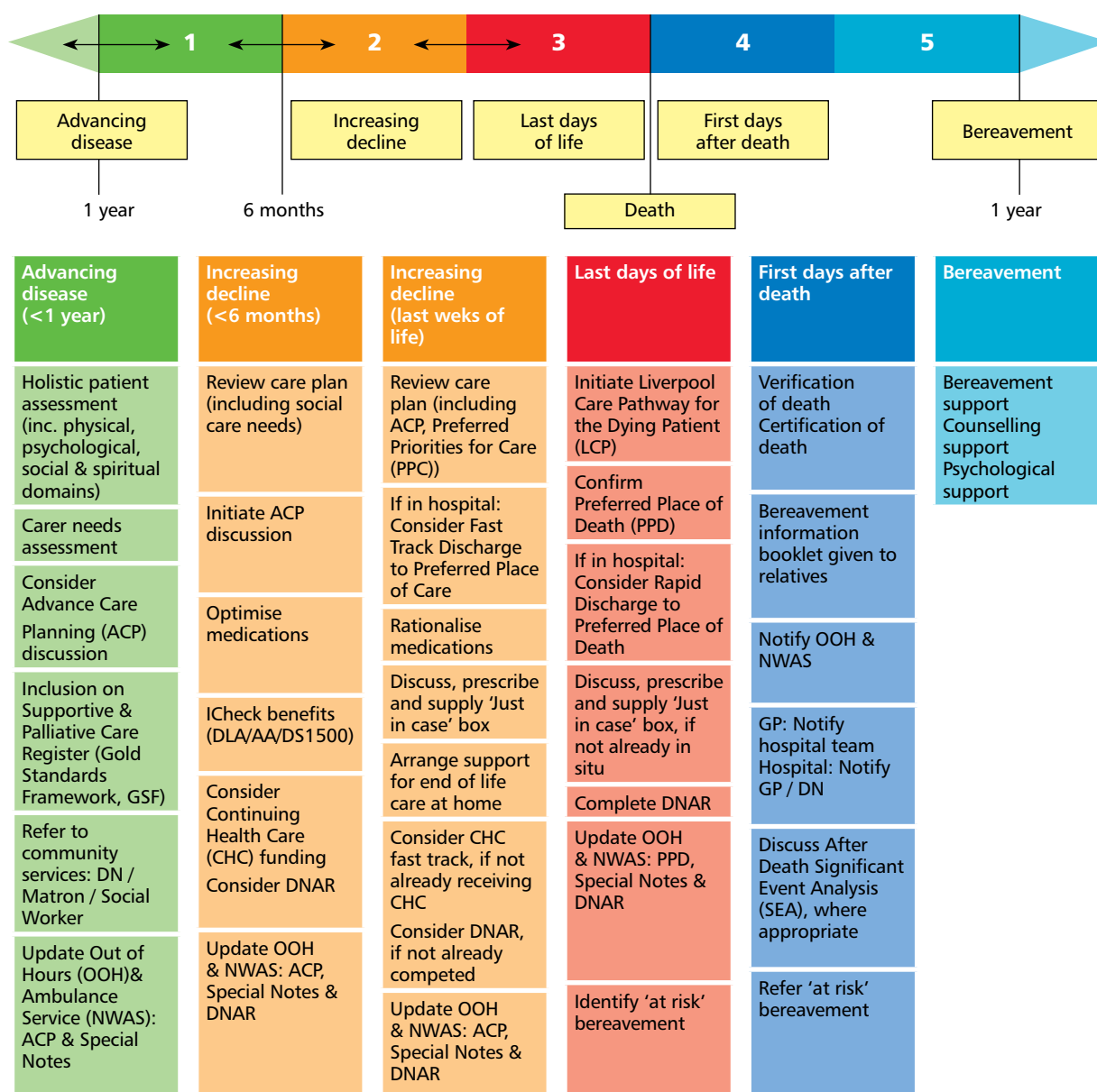


FI 2 – Blackpool Care Home Facilitation Model





FI 3 – North West end of life care model – Adapted for the Fylde Coast Health Economy



Consider referral to:

Palliative Care Services
District Nurse/
Community Matron/
Site Specific Nurse/
Social Worker
Voluntary Services
Carer support

Consider training in:

End of life care competencies training
Communication skills training
Psychological support training
Spiritual assessment training specialist

Useful Online Resources

Trinity Hospice Information for Healthcare Professionals
www.trinityhospice.co.uk/infoforprofessionals.html
Lancs & S Cumbria Palliative Care Prescribing Guidelines
fcsharepoint/Documents/PALLIATIVE%20CARE%20PRESCRIBING%20FINAL%20VERSION%202010.pdf



FI 2 – The following is a sample of the training programme run by Trinity for staff without qualifications within social care and care homes:

SLA End of Life Training Workshop Sept 2011 – Jim Cunningham Evaluation Feedback

Summary of Evaluations

Total Number of forms completed **15** (Out of a possible **15**)

Overall these 4 half day workshops achieved **97%**

1. Overall, I would evaluate the EoL Care Training

Enjoyed/brilliant, it opened my eyes to different career paths available/very informative/knowledge and confidence/interesting and diverse

2. What was the best feature of the workshop and why?

On the wings and doing hands on/Room 13, the care given after life/ gaining a better understanding/ working with Trinity nurses/death can be respectful & everyone can play a part in supporting people at eol/knowledge gained/seeing the medical side/more confidence to talk to people/evaluate useable points/ Sage & Thyme training

3. What didn't you like and why?

All the powerpoints/Sage & Thyme-too much listening not enough participation/working on the ward and giving care when needed

4. First Day – Intro to Palliative Care GSF,LCP,PPC,“Coping with Physical Symptoms”

Great/how to notice eol symptoms/better understanding/informative/more knowledge to put into practice/value based/excellent/very useful/not aware of LCP

5. 2nd Session/Working on the wings, debrief from Wings, “Needs of a person near death”

Loved it/very interesting/better understanding/opened my eyes about the services and how well patients and their needs are respected/a great opportunity and privilege/excellent/best bit of the course/gave me a real picture of Trinity/good insight/inspirational

6. 3rd Session/Sage & Thyme Training by LSCCN

Useful and informative/well put together/great template for communication/excellent training/made it easier to communicate more effectively/very useful esp. role play/fantastic framework/good to see and learn how to deal with difficult situations

7. 4th Session/care after death, Emotional issues – looking after yourself, Q&A

Loved the tree/great session/very good and a bit of fun/very effective and self reflection/excellent/useful/ very good round up/nice way to finish

Jim Cunningham – Learning & Research Co-ordinator

Session 2 – Candidates are split into 2 x groups of 8 to accommodate numbers on wings

02/02/11	End of Life Care Workshop Introduction, physical symptoms	13.00 – 16.00	Learning & Research Centre @ Trinity	Session 1
07/02/11	End of Life Care Workshop Time on the wings at Trinity	08.00 – 12.30	Learning & Research Centre @ Trinity	Session 2
08/02/11	End of Life Care Workshop Introduction, physical symptoms	08.00 – 12.30	Learning & Research Centre @ Trinity	Session 2
17/02/11	End of Life Care Workshop Introduction, physical symptoms	13.30 – 16.30	Learning & Research Centre @ Trinity	Session 3
28/02/11	End of Life Care Workshop Introduction, physical symptoms	13.30 – 16.30	Learning & Research Centre @ Trinity	Session 4



FI 5 – Trinity Hospice Resource Pack

- Collaboratively developed by Trinity, primary and secondary care, and funded by the Lancashire & Cumbria End of Life Network.
- There is an actual pack that includes three sections:
 - core resources (including localised NW EoLC Model, Primary Care Prescribing Card, Just in Case Prescribing Card, Network Prescribing Guidance, & GMC booklet on decision making at the end of life),
 - end of life care tools (including GSF & prognostic indicators, PPC & LCP) and
 - additional resources (Trinity info, Macmillan info, Dying Matters info, etc.).
- This pack is given out to all GP surgeries by the GP Macmillan Facilitators on an educational visit, and each GP is also given their own copy of the core resources to carry around in their bags with them for easy reference in the community
- All of this information is also available to download from the Healthcare Professionals section of the Trinity website. www.trinityhospice.co.uk/healthcare-professionals/resources-for-healthcare-professionals/
- The Network have also just agreed to fund packs for all other health care professionals working in primary & secondary care (e.g. DNs, Community Matrons, Hospital Teams, etc.) due the positive evaluations of these packs by GPs.

Contributors

The following people gave up time to contribute to this work:

Andrea Doherty	Lead Cancer Nurse – EoLC Project Lead – Blackpool Teaching Hospitals NHS FT
Lorraine Tymon	EoLC Project Coordinator – Blackpool Teaching Hospitals NHS FT
Kathryn Smith	Clinical Lead for End of Life Care – NHS Blackpool PCT
Janet Purdie	Care Home Facilitator – NHS Blackpool PCT
Dr Sarah Wenham	Community Consultant – Trinity Hospice
Dr Susan Salt	Medical Director – Trinity Hospice
Dr Jane Huttley	Clinical Director – Trinity Hospice
Dr Andrea Whitfield	Hospital Consultant in Palliative Medicine.



3. Profile for the Bath and North East Somerset PCT Area

The following ranges are based on publically available ONS Place of Death Indicators released for 2008/09 Q3 to Q2 compared with 2009/10 Q3 to Q2 and are expressed as deaths at home (defined as home, care homes (NHS and non-NHS)), and religious establishments as a percentage of overall deaths:

	08/09	09/10	+/-
Croydon – London Suburbs	28.9%	34.5%	5.6%
Blackpool – Coastal and Country	31.9%	37.4%	5.5%
Bath and North East Somerset (BANES) – Prospering UK	44.5%	47.5%	3.0%
East Sussex Downs and Weald – Prospering UK	43.4%	45.9%	2.5%
Bradford and Airedale – Cities and Services	47.1%	47.3%	0.3%
County Durham – Mining and Manufacturing	40.8%	40.9%	0.1%
Oxfordshire – Prospering UK	42.1%	41.9%	-0.2%

BANES at a glance

The health of people in Bath and North East Somerset is generally better than the England average. Deprivation is lower than average, however 4,180 children live in poverty. Life expectancy for both men and women is higher than the England average.

Life expectancy is 5.5 years lower for men and 3.1 years lower for women in the most deprived areas of Bath and North East Somerset than in the least deprived areas (based on the Slope Index of Inequality published on 5th January 2011).

Over the last 10 years, all-cause mortality rates have fallen. Early death rates from cancer and from heart disease and stroke have fallen and are better than the England average.

About 16.7% of Year 6 children are classified as obese. A lower percentage than average of pupils spend at least three hours each week on school sport. 86.5% of mothers initiate breast feeding and 10.4% of expectant mothers smoke during pregnancy.

An estimated 20.3% of adults smoke and 21.9% are obese. There were 3,023 hospital stays for alcohol related harm in 2009/10 and there are 251 deaths from smoking each year. Priorities in Bath and North East Somerset include partnership work to address excess winter deaths, reducing harm from alcohol and the achievement of healthy weight in children and adults. For more information see www.banes.nhs.uk

Source: www.healthprofiles.info



Basic Information:

15. Information held on Preferred Place of Death	Yes – through recognised processes but also through close interface working across services.
16. Triggers including electronic information systems	<p>EoLC register (ADASTRA) – PCT wide and also covers ambulance service.</p> <p>GP Palliative Care Registers.</p> <p>Discharge letters to GPs now include details of discussions with patients and decisions made.</p> <p>Dorothy House Hospice have a detailed electronic database and are moving this to System 1 to be able to share with GPs and also accessible to the SPC site in RUH.</p>
17. Services in the area	<p>1 main acute Royal United Hospital Bath (RUH) but cross boundary flows into Bristol and Wiltshire.</p> <p>Rheumatic Diseases Hospital in Bath Dorothy House Hospice is within the catchment area but often also work with St. Peters in Bristol.</p> <p>2 Community Hospitals</p> <p>SIRONA Care and Health – social enterprise formed from integrating health and social care services in community settings previously run by Bath and North East.</p> <p>Somerset Council and PCT Services within BANES include:</p> <ul style="list-style-type: none"> ● Community nursing 24/7 consisting of day shift then twilight and 'waking' as opposed to on call community nursing' ● Domiciliary care 24/7 ● OOHs Banes Emergency Medical Service (BEMS) ● The access team - for GPs to access with a view to putting a package of care together, facilitating admissions and discharges. ● Community enhanced pharmacy service (contracts in place with some pharmacists in BANES). BEMS OOH's service also provides OOH meds ● Hospice @ Home also supports night service with DNs in the day ● Dorothy House also provide a palliative care handbook and a 24hr advice line to help prevent avoidable admissions – this line is available to all not just GPs.
18. MDT's/ Communications	<p>Integrated working between EoLC SPC.</p> <p>EoLC Nurse at RUH and the CHC EoLC.</p> <p>Nurse Assessor provides a strong interface – meet as an operational group with DNs to discuss cases and everyone is aware of the majority of individuals at the end of life.</p> <p>Quarterly meetings CHC meetings with Dorothy House Hospice to share patient information and caseloads, demands on service etc. – works very well in BANES.</p> <p>EoLC Strategy Group at PCT.</p>
19. Protocols and Tools	<p>PCT wide DNACPR forms – Care Homes have their own DNACPR policies so can only recommend.</p> <p>Just in Case Boxes – kept in individuals' residence and hold eol meds for those in the last days of life. List agreed with palliative care consultants and pharmacists.</p> <p>Training for ACP and LCP is provided by Dorothy House education team who also raise the profile of the tools across services.</p> <p>The EoLC Operational Group help to 'bed down' the use of these tools in practice.</p> <p>LES and CQUINs in place as levers for change Fast Track process in place</p>



20. Joint working	<p>Integrated health and community care supported through SIRONA enables good domiciliary service which can be also funded by CHC if necessary e.g. equipment cupboard jointly funded.</p> <p>CHC Nurse Assessor visits Dorothy House and RUH on a regular basis.</p> <p>Dorothy House provides a significant amount of EoLC training and 24hr support.</p>
<p>21. Suggested factors that can make a difference:</p> <ul style="list-style-type: none"> ● Strong PCT Lead/Commissioning Lead (if they have a clinical background that helps) ● People in posts working as 'champions' and making change happen – success often down to individuals effort and drive ● Integrated services to smooth funding issues and provide seamless service ● Electronic information systems that are accessible across services ● Clarity on how 24hrs services will link with new 111 service ● Use of JIC boxes and noted on the register to avoid admissions ● SPC Nurses working at weekends – can impact on avoidable admissions ● Good communications across services to avoid individuals being moved to care settings 'just in case' rather than when a real need identified as can block services e.g. moved in to a hospice bed before need fully identified ● Must ensure that people get the right care package even if their PPD is within the acute setting. ● Invest in training in care homes as it has shown reduction in avoidable admissions to hospital 	

Further Information (FIs) and synthesis of discussions with a range of contributors

Considerable development on EoL services is evident through joint working across services and supported by strong leadership from the PCT. This brief summary cannot reflect all that has taken place but represents some of the key activities and contributions from all the partners working together to improve EoL services. The examples which have been provided demonstrate some of the work in more detail.

Registers – Considerable effort and investment has been made in introducing the EoLC register (ADASTRA) which includes supporting education and training which started within primary care and RUH will be the last phase for training. It does help to coordinate packages of care and in one care home it has resulted in no avoidable admissions since its introduction. One benefit is that it does cover ambulance services. Dorothy House Hospice is introducing System 1 to link with GPs and it will also be fully accessible to the SPC team in RUH.

The PCT has begun to see improvements through its use of **CQUINs** as well as introducing **Local Enhancement Schemes (LES)** related to care homes (See FI 1). The CQUINs for the Acute Trust includes an indicator on 'Patient dying in the place of their choice' plus a further three indicators to support EoLC schemes – evidence of increased training numbers, implementation of EoLC registers, and reduction in number of hospital deaths for patients aged 65 years and over. CQUINs are also in place for Sirona, Dorothy House Hospice and RNHRD.



FI 1 – PCT use of LES in Care Homes with Nursing

Significant work has been undertaken to support GPs in developing enhanced services for Care Homes with Nursing (CHwN) through the Local Enhancement Scheme process. GP Practices are currently being invited to submit expressions of interest for a LES running up to 2013. The LES was drawn up in conjunction with GPs with special interests in this area and members of the local Care Home Task Force Group (CHTFG). Briefly the key elements to be delivered are:

- Named lead GP and deputy GP to be active lead for residents and communication link with care home management
- Minimum of weekly “ward round” with all new residents to be seen and assessed by the lead GP or deputy within five working days of admission
- All residents returning from hospital admission to be seen within five working days of readmission
- Advance care planning documentation linked to all of CHwN resident patients GP records. The GP practice will need to ensure that any special instructions are provided to the Out of Hours (OOH's) provider via the Adastra End of Life Care register or Adastra special notes alert screen and updated where appropriate.
- Medication review on admission and in all clinical reviews for unstable residents with a minimum of six monthly medication reviews by GP or pharmacist for all other residents.
- All GP records to have next of kin or equivalent contact numbers. As of the end of November over half of the practices have expressed an interest which will cover a significant number of care home beds.

For further information contact: sue.townley@banes-pct.nhs.uk

The joint working between the **SPC EoLC Nurse in RUH and the CHC Nurse Assessor** has had a significant impact on improvements in moving appropriate individuals from the acute setting to their preferred place of care. The CHC Nurse Assessor goes to RUH and other acute settings when people have been identified as dying and discusses with the acute team and families which care setting is appropriate and if the facilities are available. She tries to meet the family during visiting hours to ensure that she can talk to them about decisions and care plans.

The CHC service gets around 200 referrals a year from the acute service. FI 2 describes the role of the CHC Nurse Assessor in more detail. The CHC Nurse Assessor also happens to be the ‘Dignity Champion’ across both the acute and care homes services. Better care packages identified early enough also avoid unnecessary admissions to hospices, for example patients with MND often went in to hospices to die but now a suitable care package can support them in more appropriate settings.



FI 2 – The role of the In reach CHC Nurse Assessor

The acute hospitals all complete a fast-track tool once agreed by MDT that a patient has reached a stage in their illness that their condition is rapidly deteriorating and entering a terminal phase.

This is faxed across to the CHC office and is received by the CHC Assessor and read through to check that the information meets the fast-track criteria.

The Assessor then contacts the hospital ward to acknowledge the fast-track and discusses with the nurse looking after the patient any further details that may help with the assessment process. This could be questions like is the patient able to answer questions on their Preferred Place of Care, are the family contactable and what are their contact details? do they visit the ward? Do they want to help with the care or do they feel they prefer carers to do it.

The Assessor would then try to meet the patient with the family on the same day or the next day if the family or relative is able to come to the ward to meet with the patient and the Assessor. This way a lot of the communications are covered with the family/relative all said in one place with everyone clear on the patient's wishes and the role of the CHC assessor in providing End Of life Care either in a home setting or a Care home.

Information is given about the funding and the review of the care being provided, so everyone knows that if for any reason the care had to be reassessed because the patient had become stable it not a shock and a disappointment.

The Assessor also speaks to the OT'S and Physio's about equipment and dates it will be delivered to the home to make sure it's available and in situ ready for the start of any packages of care which the assessor also organises to suit the care needs of the patient.

Palliative care team is also contacted to check for follow up at home for patient and family support. The District nurse is also contracted to see the patient within the next 24 hrs. and take over the care of the patient all details given to them if the patient goes home.

When a patient has chosen a Placement for their Preferred Place of Care the Assessor would have a list of Care homes in the area with vacancies she had already checked to give to the relatives so they could go off and look at rooms which may be suitable and then contact the assessor after a day or so, she could check funding agreement and the patient would hopefully be able to assess fairly quickly by the Care home manager and leave hospital.

For further information contact:

Karen Riddle – CHC Nurse Assessor – Karen.Riddle@sirona-cic.org.uk

Dorothy House Hospice

Dorothy House Hospice provides a Hospice at Home EoL service which has been delivered in a range of settings including care homes, sheltered housing as well as a caravan and a canal boat. The service can be:

- Usually within the last 14 days of life
- 24 hours a day
- 10pm to 7am night shift
- Always a minimum of 3 hours
- Available to all irrespective of disease
- Available as respite care for carers if they are taken ill.

The Hospice has adopted a flexible approach to staffing these services by employing 12 FT staff but maintaining a bank of about 30 staff who are available on a flexible contract basis to meet needs as they arise. More details on H@H service delivered by Dorothy House Hospice is given in example 3.



FI 3 – Home is where the heart is

Most Dorothy House patients want to stay at home during their last weeks of life, surrounded by family and friends. The Hospice at Home service helps them to do just that, supporting patient and family through difficult times.

Looking after people in their own homes has always been one of the core aims of Dorothy House Hospice Care – and it's what the Hospice at Home team excels at.

The team was originally set up as a 'sitting service' – providing overnight support for people who wanted to remain at home for their last weeks or days of life. It later became the Family Carer Service, reflecting the philosophy that the carers were there not only for the patient, but for the family as well. Now known as Hospice at Home (or H@H), the service has developed and expanded to meet growing demand.

H@H is a nursing service that offers palliative care to patients with complex needs in the last three months of life. The service is provided to patients at home, in residential care homes or other settings. A key aim of the service is to help people avoid hospital admissions, and to speed up discharge for those who have received hospital treatment, in line with the government's national end of life care strategy, which recognises that the majority of terminally ill people would prefer to die at home. The service is not restricted to Dorothy House patients, either – referrals can be made by a variety of health professionals, including Dorothy House specialist nurses and district nurses.

In 2009/10, the H@H team provided 20,000 hours of care to patients in their last three months of life. This care may include a couple of nights' respite for a family member to enable them to get a good nights' sleep or perhaps care during the day so they might go shopping or have time to themselves. As the patient reaches the final days of life, the care may be increased to every night, or 24-hour care.

The team covers all the Dorothy House geographical area and works alongside both health and social care community services. "We both supplement and complement the services they provide," says Hospice at Home manager Sue Arthur-Stevens.

"The service is delivered by health care assistants who are trained specifically in end of life care, managed by a senior specialist nurse. It is co-ordinated by experienced registered nurses with the assistance of an administrative co-ordinator. More efficient working has been achieved by replacing two registered nurse co-ordinators with an admin co-ordinator overseen by a registered nurse."

Sue added: "During the latest review of H@H services, it became apparent that the co-ordination of the service needed to extend its working hours. This was to ensure that the H@H carers are more supported, that there is an effective and efficient use of H@H carers seven days a week and that we are more accessible to our referrers."

The H@H office is now open 8am to 7pm Monday to Friday and 10am to 4pm weekends and bank holidays. The extension of the co-ordination element of the service has been generously funded by the Roper Family Charitable Trust.

In practical terms, the H@H team not only make sure the patient is safe and comfortable, but also support family members. This can involve enabling regular carers to get a good night's sleep; stepping in to provide extra care at a stressful time – over Christmas, for example; making it possible for people to attend special events, such as a wedding, by either accompanying the patient or staying with them at home so the family can attend, or by simply supporting carers in looking after a terminally ill loved one.

The service is highly valued by carers. As one explained: "It's vital. I can't praise it highly enough. Knowing I can sleep means I can manage, whatever comes at me during the day. I don't think I could do this, keeping my husband at home, if not for the night care."

Another carer said: "I felt lost at Christmas and didn't know how I would cope. Then the specialist nurse came and organised H@H. The relief was tremendous and I knew I had someone to call if I needed to."



Perhaps the last word should go to another family member, who summed up just why H@H is so important to our patients and their families: "I could not have kept mum at home without your help at nights – I would have gone under. Hospice at Home is like the cavalry!"

"I just don't know where you get the Hospice at Home carers from – they have this presence about them. Heartfelt thanks from all the family"

"The Hospice at Home service is wonderful – we feel safe when your carers are involved" "We can't thank you enough for all the care and concern when my husband was so ill."

We were so grateful to you for organising the lovely nurses who came at night to look after him, so we could have a night's sleep. Their expertise and dedication shine though"

This one is from a GP: "The Dorothy House service is first class. The care and support you give is exceptional" "Without your help the family wouldn't have been able to get through these tough times"

"You were all so kind and considerate and Mum loved you all very much!" "You are marvellous!"

"You were caring, sensitive and, when necessary, sufficiently direct in helping us through this difficult journey"

"Thank you all so much for everything you did to make my Dad's last days as comfortable as possible. I couldn't have asked for a nicer bunch of girls and I applaud you all on a fantastic job"

"Mum felt safe and cared for whenever you were involved and her peaceful end was due to your kindness and love and medical advice"

For further information please contact:

Sue Arthur-Stevens (Hospice at Home team leader)
sue.arthur-stevens@dorothyhouse-hospice.org.uk or

Sarah Whitfield, Chief Executive,
sarah.whitfield@dorothyhouse-hospice.org.uk

Contributors

The following people gave up time to contribute to this work:

Sue Townley	Project Manager, EoLC Commissioning – BANES PCT
Rachel Davis	SPC Nurse at RUH/ EoLC Facilitator
Karen Riddle	CHC Nurse Assessor – SIRONA Care and Health
Sarah Whitfield	CE, Dorothy House Hospice



4. Profile for the East Sussex Downs and Weald PCT Area

The following ranges are based on publically available ONS Place of Death Indicators released for 2008/09 Q3 to Q2 compared with 2009/10 Q3 to Q2 and are expressed as deaths at home (defined as home, care homes (NHS and non-NHS)), and religious establishments as a percentage of overall deaths:

	08/09	09/10	+/-
Croydon – London Suburbs	28.9%	34.5%	5.6%
Blackpool – Coastal and Country	31.9%	37.4%	5.5%
Bath and North East Somerset (BANES) – Prospering UK	44.5%	47.5%	3.0%
East Sussex Downs and Weald – Prospering UK	43.4%	45.9%	2.5%
Bradford and Airedale – Cities and Services	47.1%	47.3%	0.3%
County Durham – Mining and Manufacturing	40.8%	40.9%	0.1%
Oxfordshire – Prospering UK	42.1%	41.9%	-0.2%

East Sussex at a glance

The health of people in East Sussex is generally better than the England average.

Deprivation is lower than average, however 18,275 children live in poverty. Life expectancy for both men and women is higher than the England average.

Life expectancy is 8.5 years lower for men and 5.9 years lower for women in the most deprived areas of East Sussex than in the least deprived areas (based on the Slope Index of Inequality published on 5th January 2011).

Over the last 10 years, all-cause mortality rates have fallen. Early death rates from cancer and from heart disease and stroke have also fallen and are better than the England average. About 17.7% of Year 6 children are classified as obese. A lower than average percentage of pupils spend at least three hours each week on school sport. 80.8% of mothers initiate breast feeding and 16.2% of expectant mothers smoke during pregnancy.

An estimated 20.7% of adults smoke and 24.7% are obese. The rate of road injuries and deaths is higher than average.

Priorities in East Sussex include circulatory diseases, cancers and respiratory diseases for addressing the life expectancy gap between the most and least deprived areas. For more information see www.eastsussex.nhs.uk or www.eastsussex.gov.uk

Source: www.healthprofiles.info



Basic Information:

22. Information held on Preferred Place of Death	Part of the DN performance data collection process GPs have palliative care registers.
23. Triggers including electronic information systems	<p>GPs, DNs and Consultants. More work being undertaken linked particularly to the E. Sussex Advance Care Plan tool. QIPP project involves workforce development to skill staff to ensure at that they are skilled to identify when someone's health status changes to end of life pathway.</p> <p>No EoL locality register at the moment but work currently underway to get agreement on the web based register – currently use summary records with additions. Once data agreed would include through LES process.</p>
24. Services in the area	<p>E. Sussex Health Care Trust covers acute and community – just restructured to have 8 primary care access points and a group has been set up to identify cross cutting teams such as EoL.</p> <p>4 SPC teams work in the community arm of the Trust Other SPC teams in hospices Hospices:</p> <ul style="list-style-type: none"> ● St Michaels – H@H service ● St Wilfred's – H@H service ● St Peters/St James 400 Care Homes – project to establish baseline and develop facilitators to support training 24/7 services: ● DNs 8am to 10pm ● 10pm to 8am integrated night service – still DNs but a reduced service ● Urgent care palliative care pathways have been developed to support single point of access for referrals from professional.
25. MDT's/ Communications	<p>Between Hospice, SPC teams, DNs and Macmillan Nurses as well as Palliative Care Consultants.</p> <p>GP Practices that are signed up to the Palliative Care LES hold monthly meetings.</p>
26. Protocols and Tools	<p>LCP Facilitator in post – ACP being introduced and being linked to LCP and DNACPR training .</p> <p>NEoLCP Tools very valuable.</p> <p>GSF and PPC at various stages of implementation.</p> <p>Adoption of SE Coast principles of DNACPR Care after Death protocols being updated.</p>
27. Joint working	<p>Social Care Strategic Commissioner is the Chair of the EoLC Programme Board.</p> <p>On-going on a joint policy on work and interventions with county council.</p> <p>Wider public engagement on priority setting, ACP tool development ASC involved in the wider development of EoLC.</p> <p>Health commissioned input to the updated Care Home contract to include competences, ACP, LCP, PPC/D.</p> <p>Engagement with the Older Peoples Partnership Board.</p> <p>Close working with Hospices and MND Association.</p> <p>Integrated working between health and social care signed up at a strategic level to the Integrated Plan for Health and Well-being which will move toward becoming the East Sussex Health and Well-being Board.</p>



28. Suggested factors that can make a difference:

- Raising awareness on ACP early enough and sharing outcomes
- Strong Partnership working
- SPC teams to advise and train others
- Consistent policies and a universal form for DNACPR including ambulance services – do not underestimate efforts in securing legal and professional sign up and getting agreed in individual service policies and protocols
- QIPP focusses the mind and is a key driver especially with acute admissions avoidance – having leadership from the QIPP EoLC lead covering Sussex has focussed and enables a lot of good things to happen
- EoLC pathway is joined up and widely understood by all those interacting with it – right people in place to drive it.
- Integrated training of staff to gain confidence and competence
- Integrated working between LTC and specialist nurses to identify trigger stage
- EoL register with MDS in place
- Use of VOICES
- Good discharge and rapid discharge planning in place

Further Information (FIs) and synthesis of discussions

Appointing a QIPP EoLC lead across Sussex has been critical to the success in taking forward a range of initiatives especially around care homes and training.

Programmes and Projects in progress:

- Contract work with the OOHs, DN services and Care Homes to include EoLC core competences and occupational standards and use of EoL tools including PPC/PPD, elearning, GSF, ACP and care after Death.
- Performance reporting on activity of these and exception reporting on patients that have not died in their preferred place of death
- Development and provision of workforce learning and development to support staff develop skills to support people to be cared for in the community setting through high quality care and avoidance of unnecessary admission to hospital and death in hospital if not appropriate
- Working with Residential Care Homes Association who have welcomed more involvement with health and social care organisations and the introduction of ACP and community nursing palliative care support.
- Sussex wide working – working closely with EoLC colleagues and other partner organisations across the whole of Sussex to develop a high quality workforce and deliver the national EoLC strategy
- MND Association – Working with regional MND association to pilot the national volunteer training on ACP
- Confirmation is expected within the next few weeks of having CQUIN targets for both the acute and community provider across East Sussex for 2012-13 for ACP and LCP. This combined with the DN coding being significantly improved and linked to the DN contract performance management should make difference in delivery of EoLC and meeting patient needs and wishes. Workforce funding is being used to support staff to make these changes to their current practice and skills to support this.

The following are more detailed information on three current initiatives with East Sussex.

- QIPP East Sussex Nursing & Care Homes Support Project (FI 1)
- Extract from E.Sussex EoLCP ACP Leaflet (FI 2) - Note: Weston Hospice Care deserve the credit for producing the original documentation from which E. Sussex ACP has been developed
- East Sussex Summary of pilot training to develop ESHT community staff in delivering care to patients at end of life throughout the pathway (FI 3)



FI 1 – QIPP East Sussex Nursing & Care Homes Support Project

A joined up project across 400 Care Homes – Urgent Care, Social Care, Medicines Management, Dietetic, Dementia and EoLC colleagues have teamed up as part of QIPP to improve the quality of care in care homes and provide support to staff to improve their skills and behaviours.

An initial visit is undertaken to a care home by the team to assess support needs and agree an improvement plan with the home. A coordinated approach between the teams to cover nursing and care competences, fall prevention, medicines, end of life care, dementia etc. is agreed as needed.

The initial focus has been on the homes with highest needs. Care Home Project Performance Indicators covering the whole project will include:

- Emergency Admissions
- Ambulance Responses
- Falls and Fractures
- Medicines
- End of Life Care:
 - ACP
 - PPC
 - LCP
 - Emergency admissions
 - Deaths in Hospital
 - Use of DNACPR

The aim of the EoLC support is to provide services which have been pump primed to support care home staff to provide good quality EoLC to meet the residents and family needs. EoLC team lead by the hospices will use EoLC emergency admission data and urgent care data on Care Home resident attendances at hospital. Multi-disciplinary approach with support from Hospice Medics and training department, GP liaison, ESCC Quality Monitoring team, wider Care Home project linked to Urgent Care. Initial contact made to the senior management of the care home by the SPC nurse combined with a joint letter of support to the Care Home from the PCT and ASC. Although Homes with high referral rates for emergency admissions to hospital will be considered a priority it is recognised that some flexibility needs to be built in and consideration of the number of beds in the home, and the type of care home will need to be undertaken by the SPC teams.

If participating the Care Home should agree to ensure that staff have access to and are encouraged and supported to use nationally recognised end of life care tools such as ACP, PPC, LCP, SE Coast DNACPR principles. Reporting mechanisms are in place.

Further information from **Kay Muir**, Programme Lead, End of Life Care Kay.Muir@esdwpct.nhs.uk



FI 2 – Extract from E.Sussex EoLCP ACP Leaflet

PLANNING AHEAD

A RESOURCE FOR PATIENTS AND THEIR CARERS

This document has been reviewed and agreed upon by health care professionals and users involved in end of life care strategic development in East Sussex. We are grateful for Weston Hospice care for their permission to adapt their original documents.

This document is designed to help you think ahead and make any practical arrangements or decisions in advance of a crisis.

We would recommend that you talk through the issues raised with a friend, family member, doctor or nurse involved in your care. This will help you to be clear in your decision-making and also ensures family and professionals are more aware of your wishes and concerns.

For some, a useful part of the whole process is to have a discussion about the future. There may be certain areas of discussion about the future that are more relevant at any one time. It may be appropriate to come back to the other sections at a later date.

This document is formed of four sections. At the back of each section are forms that you can use if you so wish. Do not worry if you do not feel like completing a form; you may decide that having an open discussion is enough for you and you do not wish to put anything in writing. The sections are:

1. Preferred Priorities for Care – your advance wishes
2. Putting your affairs in order and making a will
3. Appointing someone to make decisions for you in the future
4. Writing an advance decision (to refuse a treatment).

The 'preferred priorities for care' can be very useful as it ensures that everyone has an overview of your wishes for how you would like to be cared for.

Appointing someone to make decisions for you – a lasting power of attorney (LPA) or writing an advance decision is something which is likely to be appropriate for only a few people. These involve legal processes and documents. It may be helpful to know they exist and to talk through them with an appropriate professional involved in your care to see if they would be useful for you.

Key references/useful websites

www.endoflifecareforadults.nhs.uk

www.adrt.nhs.uk

www.goldstandardsframework.nhs.uk

www.stwhospice.org

Contact: **Kay Muir** for a full version Kay.Muir@esdwpct.nhs.uk



FI 3 – East Sussex Summary of pilot training to develop ESHT community staff in delivering care to patients at end of life throughout the pathway

1. Introduction

The current End of Life Programme included funding to ensure workforce development and access to relevant e learning, for staff in the community delivering end of life care, particularly those who work in generic rather than specialist roles. This pilot develops training to meet the QIPP targets and also to support the Community Macmillan Specialist Cancer and Palliative Care team members to develop their knowledge and experience in relation to syringe drivers.

2. Context

The current District Nurse contract is being finalised and will include specific targets in relation to the delivery of end of life care. The Trust has had a number of significant events in relation to end of life care and currently has a dedicated facilitator to deliver training to every nurse and other appropriate clinicians in the community, to be able to use version 12 of the Liverpool Care Pathway for patients approaching death. In order to support the LCP within the context of advance care planning and to meet the standards required by NICE, community staff also need to develop competencies across a range of skills: safeguarding, mental capacity, communication, consent, confidentiality and reflection. At the same time, those who act as key clinicians may wish to be able to verify death and act as a delegated signatory for Do Not Attempt Resuscitation orders. In addition, those who deliver personal care and more tasks orientated nursing need to understand their role in the multi-disciplinary team. Alongside this, it is vital each member of the multi-disciplinary team can access appropriate e learning modules and work together well operationally.

3. Key Aims

To develop a workforce that within their competency framework can:

- understand and differentiate between specialist and generic end of life care
- undertake difficult conversations and advance care planning for end of life care
- recognise approaching death
- communicate well and deal with conflict in relation to patients' end of life journey
- act as a DNACPR delegated signatory
- undertake verification of death with the out of hours patient where they are the key clinician
- lead multi-disciplinary team members on reflective practice in end of life care
- understand their role in the multi-disciplinary team
- access e learning appropriate to their competency framework
- work together to manage symptom control for example via use of syringe drivers
- work together to deliver an integrated care pathway during the dying process e.g. Liverpool Care Pathway



4. Evaluation

- Number of patients receiving end of life care in their preferred place of care
- Number of patients who did not achieve end of life in their preferred place of care with analysis of causative factors
- Number of patients on the Liverpool Care Pathway at end of life and key learning points from same
- Number of patients not on the Liverpool Care Pathway at end of life and exception reporting for expected deaths
- Reduction in number of complaints and significant incidents in relation to end of life care
- Reduction in number of inappropriate resuscitations and admissions into hospital in last hours or days of life
- Reduction in delay of delivery of care, due to difficulty in handover to other members of the multi-disciplinary team
- Improved understanding across the multi-disciplinary team of their differing roles and responsibilities
- Improved access to e learning for relevant clinicians in the Trust – number of e learning modules accessed by staff and their roles.

For further information contact **Kay Muir** Kay.Muir@esdwpct.nhs.uk

Contributors

The following people gave up time to contribute to this work:

Karen Devanny

SHA EoLC Lead

Kay Muir

Programme Lead, End of Life Care

– NHS East Sussex Downs and Weald, NHS Hastings and Rother



5. Profile for the Bradford and Airedale PCT Area

The following ranges are based on publically available ONS Place of Death Indicators released for 2008/09 Q3 to Q2 compared with 2009/10 Q3 to Q2 and are expressed as deaths at home (defined as home, care homes (NHS and non-NHS)), and religious establishments as a percentage of overall deaths:

	08/09	09/10	+/-
Croydon – London Suburbs	28.9%	34.5%	5.6%
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East Sussex Downs and Weald – Prospering UK	43.4%	45.9%	2.5%
Bradford and Airedale – Cities and Services	47.1%	47.3%	0.3%
County Durham – Mining and Manufacturing	40.8%	40.9%	0.1%
Oxfordshire – Prospering UK	42.1%	41.9%	-0.2%

Bradford and Airedale at a glance

The health of people in Bradford is generally worse than the England average. Deprivation is higher than average and 37,705 children live in poverty. Life expectancy for both men and women is lower than the England average.

Life expectancy is 11.9 years lower for men and 7.2 years lower for women in the most deprived areas of Bradford than in the least deprived areas (based on the Slope Index of Inequality published on 5th January 2011).

Over the last 10 years, all-cause mortality rates have fallen. Early death rates from cancer and from heart disease and stroke have fallen and the latter is worse than the England average.

About 19.8% of Year 6 children are classified as obese. A lower percentage than average of pupils spend at least three hours each week on school sport. Levels of teenage pregnancy, GCSE attainment and tooth decay in children are worse than the England average.

Estimated levels of adult 'healthy eating' and obesity are worse than the England average. Rates of smoking related deaths and hospital stays for alcohol related harm are higher than average. Priorities in Bradford include addressing health inequalities, obesity, alcohol, tobacco and tackling infant mortality. For more information see www.observatory.bradford.nhs.uk

Source: www.healthprofiles.info



Basic Information:

29. Information held on Preferred Place of Death	<p>GPs maintain palliative care registers. The Bradford Community Specialist Palliative Care Team use a template developed by NHS Bradford and Airedale EoL work stream led by a Lead GP and Consultant in Palliative Medicine and is being rolled out across the locality for System One to facilitate collection of data such as PPD, DNACPR and has supported 7 DN being trained in its usage.</p> <p>Within SPC Teams services 60% of individuals have PPD recorded.</p> <p>Within CHC Fast Track and Hospice at Home provision 95% of individuals have PPD recorded and 70% achieve PPD.</p>
30. Triggers including electronic information systems	<p>Triggers – GPs, DN visit, MDT, discharge letters, home care etc.</p> <p>System One is well established in Bradford as it was developed by a local Airedale GP. System One is the preferred system for locality registers. It contains demographic detail, medical notes and care, care visits and EoL plans. It is available between acute (very limited to acute services except SPC teams), all SPC providers, GPs, OOHs and DNs. At the moment not available to ambulance teams.</p> <p>System 1 is compliant with Connecting for Health for palliative care.</p> <p>Fast access funding for continuing care automatically registers with the 'hospice at home' service.</p>
31. Services in the area	<p>Acute Hospitals – Bradford Royal Infirmary & St. Luke's Hospital and Airedale General; Hospices – Marie Curie in Bradford – 16 beds and Sue Ryder Manorlands Hospice in Keighley – 16 beds with SPC team 92 Residential Care Homes and 62 Nursing Homes.</p> <p>Palliative Care Nurses are linked geographically to GPs 24/7 Cover:</p> <ul style="list-style-type: none"> ● GPs during the day and OOH GPs at other times ● SPC community teams (in hours) and on call consultant in palliative medicine (OOH and weekends) ● Hospice at Home 8am to 10pm then night time DN service ● 24hr pharmacy ● Marie Curie provide night care ● Single point of access – call handler either deals direct or takes details and contacts relevant people. <p>CHC Fast track commissioned service from social care is flexible and may substitute sessions with palliative care cover in some cases.</p> <p>Sue Ryder Manorlands Hospice fund a community team comprising a medical consultant, 6 specialist nurses and access to other hospice staff as necessary.</p>
32. MDT's/ Communications	<p>Managed Clinical Network – strategy group undertaking PCT wide planning as well as a clinical governance, education etc. and links in with the PCT EoLC Programme Board whose members include commissioners, SPC, hospices, social care lead and GPs.</p> <p>Some MDT meetings include patients, family and other involved closely with care.</p>
33. Protocols and Tools	<p>Care after Death is LCP based DNACPR is PCT (joint policy with community, hospitals, hospices, care trusts etc) and SHA has single SHA wide DNACPR form and patient information leaflet.</p> <p>Fast Track for those in the last few weeks of life offers a streamline process with good coordination and Hospice at Home services</p> <p>Where GSF is used well and includes multidisciplinary teams, planning and follow up it provides a good experience for patients.</p>



34. Joint working	<p>Bradford Community Specialist Palliative Care Team facilitate joint working across services.</p> <p>Rotation of SPC Consultant posts across Acute, Community Team and Hospices. Close working with ambulance services at high level – when patient is recognised as receiving palliative care ambulance staff should call the DN in the first instance and there is a target of half an hour response. Good relationship with voluntary sector – MND, MS Society, LD and MH.</p>
35. Suggested factors that can make a difference:	<ul style="list-style-type: none"> ● Interested commissioners who want to reinvest and redesign across boundaries ● Clinical leaderships with a vision to make things happen ● Champions across all areas ● Rotational SPC posts across acute, community and hospice care ● Support to care homes to enable people to receive care in situ rather than unnecessary acute admissions ● Early identification of preferences and being able to record changes in PPD when an individual's circumstances change ensuring everyone involved with the care picks this up ● SPC take an active role in the acute setting at raising awareness of EoL, ACP etc and how discharges can be achieved earlier utilising CHC fast track if appropriate ● Good embedded GSF with follow through ● Electronic based patient record systems that can be widely shared and avoid duplication ● Coordination of care ● Funding decisions between health and social care simplified – pooled budgets ● More work undertaken around those who live on their own and want to die at home.

Further Information (FIs) and synthesis of discussions with a range of contributors

Bradford has a significant ethnic population but from a similar background so cannot be called a diverse ethnic population. In a survey of those referred to the Community SPC Team 86% were white British, 6% Asian, 3% European, less than 1% Caribbean, 1% unknown and 4% others. Sue Ryder Manorlands Hospice are undertaking a project to increase access and referrals to palliative and end of life services among BME groups by recruiting BME apprentices to train in NVQ level 2 health and social care.

All of the apprentices have moved on to permanent posts or further education some within palliative care. The service has also increased the local BME communities' involvement in end of life care services.

Within the PCT area considerable work has already been undertaken on improving end of life services and the existence of the Managed Clinical Network strategic group for end of life was highlighted by many as a key factor in providing a seamless service. The success of this strategic group has also facilitated links with Bradford University resulting in education posts.

In addition Bradford District Care Trust has a Community Specialist Palliative Care Team coordinating and providing end of life services that cover the PCT area and provide Hospice at Home care. This team comprises of:

- A Clinical Lead,
- Macmillan Nurse Specialist
- Consultant in Palliative Medicine (rotational post)
- Social Worker
- Ethnic Liaison Worker
- Bilingual Worker
- Psychologist
- Macmillan GP Facilitator.



Case Study 1 (FI 1) illustrates an example of their work.

Significant investment also appears to have been made in education and training. Apparently training of HCAs and general staff in palliative care has been undertaken for a number of years with a training programme specifically for DNs in place. An education strategy exists and covers delivery of training in evenings, 2 day district wide palliative care training days delivered across four different sites each year including care home based training, and communication skills training using ACST and the e-ELCA communication skills training programme. Bradford Teaching Hospitals have been proactive about education through local CQUINs.

Sue Ryder Manorlands Hospice is the 'rural' provider in the area and has a higher number of those dying at home as a result. They are supportive of the consultant rotational posts which, from all spoken to, were seen as beneficial and facilitated joint working. Clearly linkages between the hospice, the community SPC team and the acute hospitals worked really well.

The hospice does not operate a waiting list as this has shown to encourage early referrals (just in case) and causes problems. They use a single referral form and admit people 24/48 hours after referral and all referrals are reviewed at 9am each day. This has shown to keep the process moving quickly. The Hospice provides a 24 hour advice line for professionals.

Other projects mentioned during discussions include:

- Verification of Death
- Reasons for unplanned admissions
- Support for the last year in life – just finished but the report is not available yet.

FI 1 – Case Study from the Community SPC Team

Bob 49,

Previous history- IV drug user, Heb C+ and alcoholic.

Had previously been homeless, but over the past 12 months had settled into supported living. Was well supported by carers in the accommodation. Bob had collapsed at home, admitted to Hospital and given a prognosis of days.

His preferred place of death was back in his supported living. CHC Fast track was contacted by Hospital Palliative Care Team to plan discharge. Carers within his supported living keen for Bob to return home. Bob was assessed on the Ward, expressed a wish to return to supported living. Bob was settled most of time, but still wanted to get up to go to the toilet. His symptoms were well controlled.

On assessment of home, Bob lived in a two storey purpose built accommodation. He had a room upstairs; other residents were asked whether they would swap room. They all refused as they were concerned about after Bob's death returning to the room.

It was decided to manage Bob in his own room, although staff would not be able to supervise Bob all the time, there was a Careline system. Careline were contacted and a under mattress sensor was installed. This would alert the staff if Bob was trying to get out of bed.

A profiling bed, pressure relieving mattress, commode, urinal and handling sheets were ordered and delivered to the home. Marie Curie Night care was arranged to cover from 10pm till 7am. The Hospice at Home/District Nurses were arranged to visit 4 times a day to provide care, provide support to the carers and monitor symptom control.

Bob came home on the Liverpool Care Pathway and died that evening.



Contributors

The following people gave up time to contribute to this work:

Charlotte Rock	Macmillan CNS Palliative Care Bradford Teaching Hospitals
Fiona Hicks	Consultant in Palliative Care – Yorks and Humber SHA EoLC Lead
Belinda Marks	Clinical Lead Palliative Care Service – Bradford District Care Trust
Steve Davison	Care Services Manager – Sue Ryder Manorlands Hospice
June Toovey	Nurse Director – Yorkshire Cancer Network



6. Profile for the County Durham PCT Area

The following ranges are based on publically available ONS Place of Death Indicators released for 2008/09 Q3 to Q2 compared with 2009/10 Q3 to Q2 and are expressed as deaths at home (defined as home, care homes (NHS and non-NHS)), and religious establishments as a percentage of overall deaths:

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County Durham – Mining and Manufacturing	40.8%	40.9%	0.1%
Oxfordshire – Prospering UK	42.1%	41.9%	-0.2%

Bradford and Airedale at a glance

The health of people in County Durham is mixed compared to the England average. Deprivation is higher than average and 22,805 children live in poverty. Life expectancy for both men and women is lower than the England average.

Life expectancy is 8.1 years lower for men and 6.3 years lower for women in the most deprived areas of County Durham than in the least deprived areas (based on the Slope Index of Inequality published on 5th January 2011).

Over the last 10 years, all-cause mortality rates have fallen. Early death rates from cancer and from heart disease and stroke have fallen but remain worse than the England average.

About 20.6% of Year 6 children are classified as obese. A higher percentage than average of pupils spend at least three hours each week on school sport. Levels of teenage pregnancy and tooth decay in children are worse than the England average.

Estimated levels of adult 'healthy eating', smoking and obesity are worse than the England average. Rates of smoking related deaths and hospital stays for alcohol related harm are higher than average.

Priorities in County Durham include reducing smoking, tackling alcohol crime and reducing early deaths from cancer and heart disease. For more information see www.countydurham.nhs.uk

Source: www.healthprofiles.info



Basic Information:

36. Information held on Preferred Place of Death	Recorded on System one and within Advance Statement document. GPs maintain practice registers which includes where people die. After death analysis by GPs is undertaken to see what can be done better.
37. Triggers including electronic information systems	Last days are triggered by LCP factors Hope to have NE wide electronically coded register from January 2012. OOHs form being used by DNs, Macmillan Nurses, Community Matrons and GPs.
38. Services in the area	University Hospital of North Durham and Darlington Memorial Hospital have Macmillan Nurses and Palliative Care. Consultants and with community consultants covering community hospitals. Bishop Auckland Hospital. 3 Hospices with inpatient beds. There is also access to two other out of area hospices with in-patient beds. Day hospice is provided by 4 in area hospices (one hospice provides peripatetic day care in 3 of the community hospitals in rural areas). 6 community hospitals. One Care Home (Easington) has 2 step up nurse led palliative care beds with support from local palliative care team and elderly care physician. Admissions possible evenings and weekends. Macmillan Nurses in each locality supported by Community palliative care Consultants. Macmillan / specialist AHPs (some localities). 24/7 support provided by DNs who have access to end of life care training – OOHs DN services across Durham provided by own staff who work in the local area. 24/7 coordination centre to provide single point of access being planned. 2 Macmillan Discharge Facilitators ensure rapid discharge to preferred place of care. Macmillan Carers supporting discharges Readmission Avoidance Scheme – not just palliative care – Community Matrons lead on prevention of admission within 42 days. Rapid Access Medical Assessment Consultants (RAMAC) in Darlington and UHND.
39. MDT's/ Communications	GPs hold monthly-3 monthly – includes primary care teams and Macmillan Nurses
40. Protocols and Tools	Mixture of GSF and KITE Keep Improving the Experience (KITE) used in general practice. LCP used in care homes Uptake of ACP progressing through CQUINs.
41. Joint working	Working closely with Macmillan and Hospices. Macmillan nurses and more recently Care Close to Home Practitioners also work closely with care homes to help ensure systems are in place, and provide support and training. Work undertaken with prison services.



42. Suggested factors that can make a difference:

- Needs whole systems change not just one bit – surprise question, 1% campaign, transfer of information, DNACPR area wide protocols, coordinated care in community by maximising use of registers, LCP tools and drugs, use of CQUINS
- Multi pathway intervention to make sure people are able to make a choice about PPD at appropriate times – recognise that most people do not want to die in the acute setting.
- All sectors need to be geared up to change – Good community based services are key. If discharge systems in the acute are being set up to facilitate discharges and avoid unnecessary readmissions, the community services must also be developed in parallel otherwise delays and frustrations occur for staff and patients – need investment in the community
- No more layers of 'coordination' taking up resources – better used for providing practical 'hands on' care
- Get equipment in place – often difficult to get hospital beds in to homes – cost and availability- need for easy access to buffer stock
- Need improvements in the quality of information transfer to facilitate a seamless communications process to those close to care of the individual
- Must get buy in from all – good partnership working
- Induction period for people coming in to Discharge Facilitator roles to know what the range of care provision is and the processes in place (5 weeks in Co Durham)
- Make sure clarity around 111 services and 24hr services
- Easy access to overnight sitting services.

Further Information (FIs) and synthesis of discussions with a range of contributors

Being a rural area it is often further to go to get to an acute hospital, so more tend to die at home plus with a mining history of community spirit in some areas more support from families and neighbours is available – 'stoic' by nature.

There are two main factors which have influenced the ability within the acute setting to discharge dying patients into the community. One is the Macmillan Discharge Facilitators (MDF); the other is the Macmillan carers in the community.

Discussion has taken place regarding whether the role can be undertaken by a non-clinical person but it was agreed that the role benefits by being able to make some clinical judgements and ability to signpost to appropriate care which is critical to successful discharges.

County Durham and Darlington NHS FT has two WTE Macmillan Discharge Facilitators (Band 6) in the acute setting – one based at University Hospital of North Durham, the other at Darlington Memorial Hospital. They support rapid discharge of patients at the end of life into their preferred place of care and the discharge of palliative patients with complex needs.

The main aims of the post holders are to:

- Improve the skills of ward based nursing teams in discharging complex patients with palliative care needs
- Increase the proportion of dying patients who are managed on the Liverpool End of Life Care Pathway
- Increase the numbers of palliative care patients able to die in their preferred place of care.
- Improve the quality of palliative care patient discharge with the aim of reducing re admission rates

Their appointment in spring 2011 has already had definite impact in terms of supporting preferred place of care, timeliness of discharge and co-ordination of care (see FI 1 below). Part of their role also involves contact with community staff and carers, often a time-consuming and slow process when undertaken by ward-based nurses and this also ensures a good handover.



FI 1 – Macmillan Palliative Care Discharge Facilitator Team

–Taken from the Service Activity Report April – August 2011

An internal report has shown in the five months since the appointments have been made there have been 181 referrals to Macmillan Palliative Care Discharge Facilitator Team (MPCDFT) resulting in 155 eol patient discharges from acute care (25 died in hospital and one remained in hospital at the end of the period). Of the 25 patients who died in hospital, eight identified this as their PPC and 15 had a clinical reason which prevented discharge. One died before transfer to the Hospice could be achieved and the final patient's reasons for non-discharge are being investigated further.

Of the 155 patients discharged from the acute hospital six did not achieve their PPC and other arrangements were made with their agreement. Three could not go home as their families could not cope and two were deemed unsafe to be at home as they lived alone and were unsupported. One preferred to go to a hospice but the referral was deemed inappropriate and they transferred to a nursing home.

A total of 144 (80%) patients achieved their PPC which included patients who identified the acute hospital as their PPC at end of life (PPD). This is a very good result to be achieved over a relatively short period of time and demonstrates the impact this level of development can make.

Of the 181 referrals received during the period:

133 (73%) were cancer

48 (27%) were non-cancer

[Note: The full evaluation report was provided by Colette Hawkins, Palliative Care Consultant, University Hospital of N. Durham with permission from her Trust for which we are extremely grateful].



Macmillan Carers have had a fundamentally important role in supporting discharges back home. They respond immediately and provide invaluable support for both patients and carers. Without them, the burden of responsibility on relatives and carers and emotional pressure of caring for a dying person at home would prevent a significant proportion of our discharges. They have been introduced in to 4 of the PCT areas and are now moving in to the 5th.

FI 2 provides more detail on their role and interaction with the MPCDFT.

FI 2 – The Role of Macmillan Carers

The Macmillan Carers service within County Durham and Darlington Foundation Trust provide high quality personal care and emotional support to patients approaching the end of life.

The team comprises 16 highly skilled Health Care Assistants, usually Band 4 and 3 but some at Band 2, who have enhanced skills in communication, person centred holistic care and providing intensive support for patients who are dying (and their families). They work very closely with District Nurses and the local Macmillan team to support early discharges, prevent admissions and to support patients and families to remain in their preferred place of care. Band 4 are also expected to undertake some teaching.

The service is flexible, responds very rapidly and provides both practical support and care for patients and families.

Increasingly the team are working with the two Macmillan Discharge Facilitators in the two acute hospitals who ensure patients with end of life care needs in hospital are rapidly discharged to their preferred place of care. The Macmillan Discharge Facilitators have been able to work with A& E, Medical Admissions and all wards to ensure patients approaching end of life receive timely and appropriate investigations and treatment in hospital. They are also able to mobilise resources to ensure safe and effective discharges sometimes within hours of admission.

The Macmillan Carers are able to respond quickly to their requests for support.

Feedback from patients' carers and staff is excellent about both services – with many comments about the high levels of professionalism, respect for dignity and the focus on compassionate care. Service activity is increasing and the service is likely to expand further to meet the needs of the whole locality

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St Cuthbert's Hospice

St Cuthbert's Hospice opened in 1988, and provides specialist medical and nursing care for people with life limiting conditions from across North Durham.

St. Cuthbert's Hospice provides:

- An In-Patient Unit offering 24 hour care
- A Day Hospice offering advice, support and activities
- Treatments including Physiotherapy, Occupational Therapy and a Lymphoedema Clinic
- Community Support
- Bereavement care and support to relatives

The Day Hospice aims to help patients to promote their quality of life while continuing to live at home, and can help families by offering a break from caring duties.

St Cuthbert's Day Hospice is currently open four days per week, and provides care for up to fifteen patients per session. Patients initially attend Day Hospice for eight weeks, and their needs are re-assessed after this period.

The ten-bed In Patient Unit was opened in September 2006, and allowed St Cuthbert's to provide 24 hour care for the first time. The unit provides holistic care to patients and their carers.

The unit cares for people with complicated medical needs, and admissions are made for help with symptom management, short term planned care to support relatives and carers, and for end of life care.

The unit is staffed by a team of experienced professionals, and medical cover is supported by doctors with palliative care skills, with support by Consultants in Palliative Medicine.

FI 3 highlights further developments at St Cuthbert's.

FI 3 – Developments at St Cuthbert's

Two rapid response teams based in the hospice are being introduced in the new year as a joint project with the PCT, the hospice and Marie Curie to cover small geographic areas. These will comprise of a qualified nurse and an HCA trained in Palliative Care and be available 24/7. They will respond within an hour and be available for phone support as well.

Two further teams have already started in the south of the area based at St Teresa's Hospice.

The Hospice Consultant offers training to OOHs teams (2 hours), but when the course is offered attendance is much lower than those who initially signed up. One of the aims is to increase the confidence of OOH medics to treat within the home or care home and avoid unnecessary admissions.

The Hospice doctors train GP registrars but it is an opt-in option for rotation and not mandatory.

The MDF does not refer all discharges to the hospice as it should be only those requiring SPC – others are better suited to nursing home/care home, even if they need palliative care, as it is their home. Jointly looking at the criteria on the referral form to facilitate a smoother process.

The Hospice has links with two care homes so that if a rapid response team is called they will know what is expected – anyone who cannot be settled by the rapid response team in the care home or home then the Hospice is making two unregistered rooms available called 'assessment beds' for 48 hours. If clinically appropriate the patient can then go back home or as an alternative one of the nursing homes has identified 'step down' beds for those not fully ready. As a result nursing home staff are being trained to a higher level in palliative care.

For further information contact **Angela Dinsdale** CE St Cuthbert's Hospice
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Prison Services

Macmillan Cancer Support has worked with County Durham and Darlington Foundation Trust, commissioners (County Durham PCT) and the HMP Durham Cluster of prisons to develop a series of accredited prison standards and associated tools which should mean more people can die in prison where this is their choice and fewer will be admitted to hospital unnecessarily.

It is also hoped to reduce hospital and hospice lengths of stay, to increase the number of key staff with accredited end of life care skills and to raise the profile of palliative and end of life care within the prison community.

Contributors

The following people gave up time to contribute to this work:

Colette Hawkins	Palliative Care Consultant – University Hospital of N Durham
Kay McAlinden	Macmillan Lead Nurse, County Durham & Darlington NHS Foundation Trust
Elizabeth Kendrick	GPwSI Older people and Chair End of Life Clinical Innovation Team NHS North East County Durham & Darlington NHS Foundation Trust
Lauren Shepherd	Macmillan Discharge Facilitator
Angela Dinsdale	CE St Cuthbert's Hospice



7. Profile for the Oxfordshire PCT Area

The following ranges are based on publically available ONS Place of Death Indicators released for 2008/09 Q3 to Q2 compared with 2009/10 Q3 to Q2 and are expressed as deaths at home (defined as home, care homes (NHS and non-NHS)), and religious establishments as a percentage of overall deaths:

	08/09	09/10	+/-
Croydon – London Suburbs	28.9%	34.5%	5.6%
Blackpool – Coastal and Country	31.9%	37.4%	5.5%
Bath and North East Somerset (BANES) – Prospering UK	44.5%	47.5%	3.0%
East Sussex Downs and Weald – Prospering UK	43.4%	45.9%	2.5%
Bradford and Airedale – Cities and Services	47.1%	47.3%	0.3%
County Durham – Mining and Manufacturing	40.8%	40.9%	0.1%
Oxfordshire – Prospering UK	42.1%	41.9%	-0.2%

Oxfordshire at a glance

The health of people in Oxfordshire is generally better than the England average. Deprivation is lower than average, however 15,660 children live in poverty. Life expectancy for both men and women is higher than the England average.

Life expectancy is 5.8 years lower for men and 3 years lower for women in the most deprived areas of Oxfordshire than in the least deprived areas (based on the Slope Index of Inequality published on 5th January 2011).

Over the last 10 years, all-cause mortality rates have fallen. Early death rates from cancer and from heart disease and stroke have also fallen and are better than the England average.

About 15.1% of Year 6 children are classified as obese. A lower than average percentage of pupils spend at least three hours each week on school sport. 78.7% of mothers initiate breast feeding and 8.2% of expectant mothers smoke during pregnancy.

An estimated 17.0% of adults smoke and 20.7% are obese. The rate of road injuries and deaths is higher than average.

Priorities in Oxfordshire include tackling obesity, including increasing physical activity levels, reducing high risk alcohol behaviour and improving older people's physical activity programmes to reduce hip fractures. For more information see www.oxfordshirepct.nhs.uk

Source: www.healthprofiles.info



Basic Information:

43. Information held on Preferred Place of Death	All GP surgeries with GSF should have PPD recorded.
44. Triggers including electronic information systems	<p>EoL register and Monitoring – Oxfordshire does have a GP EoL register (Palliative care register for QOF) through the GSF. This is coded and enables the PCT to work with practices to pull information off via Health Informatics and Intelligence Team. There are a number of codes used so more specific information can be obtained when requested.</p> <p>For example, those on the EoL register, those in terminal care, those on death administration NOS (where you can pick which the person's preferred place of death is i.e. at home, in hospital) etc.</p> <p>EoL register sharing – At present Oxfordshire does not have the ability to share the register due to different IT systems used across the county. However, work is being done to improve access to this data by piloting an online tool.</p>
45. Services in the area	<p>One major Acute Trust on four separate sites.</p> <p>3 Hospices – Sobell, Sue Ryder and Katharine House.</p> <p>Oxford Health Foundation – 8 community hospitals.</p> <p>3 Community Matrons are in post.</p> <p>24 hour cover in Oxfordshire for EoL patients</p> <ul style="list-style-type: none"> ● 24 hr specialist palliative care telephone advice ● Sobell provides 24/7 and 7 day possibility of admission ● Sue Ryder Hospices provide 7 day possibility of admission ● Katharine House Hospice admits Monday to Friday ● RISE and Marie Curie provide day or night cover on a booked basis. <p>Marie Curie –within Oxfordshire, anyone referring for night services are able to indicate the number of nights that support will be anticipated, but availability cannot be confirmed until 3pm on the day itself.</p> <p>Green Bottle markers are used to assist OOHs and ambulance services access information kept in the patients home.</p>
46. MDT's/ Communications	<p>A monthly meeting of the EoLC Reference Group takes place which looks at service, locality registers, information sharing and the education group feed in as well as NHS and voluntary groups.</p> <p>GP GSF groups also meet monthly.</p>
47. Protocols and Tools	<p>Use GSF – PPD audits are undertaken by DNs.</p> <p>Unified DNACPR SHA wide.</p> <p>Unified ACP – resources document awaiting primary and secondary care governance approval.</p> <p>Oxfordshire version of LCP used (ICP) South Central Ambulance Trust have developed an Anticipatory Care Plan (ACP) to be completed by case managers, EoL Matrons, DNs etc. which will provide crews with 'normal obs' information on a patient and services they are involved with.</p>



48. Joint working

End Of Life Reference Group (which is held monthly).

A workshop was held 1 month ago to look at EOL pathway and identify gaps and was attended by all providers.

Speed dating event in North Oxfordshire held in September, attended by a large number of providers and enabled them the opportunity to promote services.

EoL is represented at both North and South West Whole System Pilots.

EoL financial modelling project which is attended by a number of stakeholders.

A workshop was held in late October to bring together all those involved in different nursing roles relevant to EoLC in Oxfordshire (palliative care clinical nurse specialists, community matrons, practice development facilitators, case managers, disease-specific clinical nurse specialists and district nurses) to clarify the distinction between the different roles so that more seamless care can be coordinated and provided.

49. Suggested factors that can make a difference:

- Identify people as soon as possible
- Shared Electronic Information Systems
- ACP and anticipatory prescriptions
- Unified protocols
- Simplified intermediate multi-professional care support services available
 - Makes referral easier
 - Less paperwork
 - Clear communication
- Basic palliative care training for paid carers
- Funding and referral process made less complex
- Good relationships with social care when responding to continuing care fast track process
- Coordinate to reduce paperwork and act as gatekeeper – but does not necessarily need more coordinators e.g. ensure it is appropriate to cancel care package if a patient is admitted
- Face to face assessment and access to therapy services
- Within the community – rapid assessment service by telephone – equipment sent out quickly
- Flexibility of care package – need to be able to go up and down as condition goes up and down
- Availability of DN service 24/7
- Support visits from GPs and DNs needed
 - Education and Training
 - Sufficient resources to ensure does not become task orientated



Further Information (FIs) and synthesis of discussions with a range of contributors

Oxfordshire benefits from having high levels of commitment and activity to improve end of life care services. This is reflected in the strategic work undertaken by the lead in NHS South Central as well as engaged commissioners at the PCT, and staff from all sectors actively working to make improvements.

At SHA level there is a clearly defined QIPP EoLC programme which as well as delivering the intended benefits also is ensuring sustainability for the future. Further information in what is happening at SHA level can be obtained from Lucy Sutton - Associate Director for End of Life Care Programme and AQP Lead Lucy.Sutton@southcentral.nhs.uk

The following are examples of some of the work being undertaken locally:

EoL Facilitators in residential homes – although EoL Practice Development Facilitators have not been commissioned to work within residential homes (only in nursing homes), they do work with the Care Homes Support Service (CHSS, within both nursing and residential homes) to share knowledge, learning and skills as well as offering support. This is then filtered through the homes via training provided by the CHSS to all staff. In addition, when required the CHSS calls upon the expertise of the facilitators to prevent an admission thus enabling people to die at home.

RISE – Rapid Intervention Service for End-of-Life-Care – This is a flexible responsive service that support the care of adult patients with any advanced, progressive, incurable illness and any additional condition e.g. mental illness or learning disability. The referral centre operates between 8 am and 10pm, seven days a week. Care and support (by health care assistants) can be provided day or night for a maximum of six days. RISE aims to assess within 4 hours of referral; referrals after 6pm may not be assessed until the next day.

If on-going care is needed after approximately 6 days the RISE team requires the referrers to ensure that other services are involved so care can be continued if necessary. Extracts from the original Oxfordshire PCT service specification for RISE can be found in FI 1.

Palliative Care Education in Primary Care – During 2011/12 the three hospices and the PCT offered training sessions to GPs and District Nurses caring for patients with palliative care needs in the community. These sessions were led by Palliative Care Consultants and were free of charge. Each session lasted an hour with one being held each week for six weeks covering a different topic. It is planned to repeat this in three differing locations between November 2011 and May 2012 with further sessions planned for later in 2012. The topics covered are:

1. Diagnosing dying and anticipatory prescribing
2. Conversations about end of life
3. Pain update
4. Managing delirium/depression
5. Palliative care emergencies
6. Update on grief

Practice Development Facilitator for EoLC – Two facilitators work across a range of initiatives including the usage of national tools. As no two PHCT teams are the same they adopted a non-directive approach and encouraged teams to consider the tools offered and to use those that would work for them.

A PHCT could be deemed to be adopting GSF if they could demonstrate the minimum required by Quality Outcome Framework (QOF) – that of having a register of those who are in the last year of life and that these individuals are discussed in a meaningful way at a regular multi-professional meetings.



Work has built upon that undertaken in the period 2005-2010. Links have been made with all general practice teams in Oxfordshire (n=82) to meet individual team needs regarding instigation or development of GSF as part of best practice for end of life care. Due to previous work, some practices utilise the tool in different ways and at different 'levels' to others with varying degrees of commitment.

At the current point of time 92% (n=75) of Oxfordshire PHCTs are using GSF, individualised to each team. All of these teams hold a register of patients estimated to be in last year of life, and have regular multidisciplinary meetings to discuss these patients in depth, to be proactive and seamless in offering care.

ICP (Oxfordshire version of LCP) - In January 2010 the percentage of teams using ICP was 63% (n=52). In April 2011 the percentage of teams using ICP was 88% (n=72). All community hospitals are now using the tool and results of audit are currently awaited from Liverpool.

Work undertaken with Care Homes can be found in FI 2.

Oxford Learning Pathways for End of Life Care Project – The Oxford Learning Pathways for End of Life Care project was launched in October 2011. The aim of this project is to develop and test a set of learning pathways for different staff groups involved in providing end of life care to people in Oxfordshire. These pathways will build blended learning around the national e-ELCA programme, and will be informed by on-going evaluation.

The pathway development will be guided by experienced clinicians and educators in palliative and end of life care, and will sit within a wider evaluation framework. Those involved in pathway development will have the opportunity to contribute to these plans as well as develop themselves as facilitators of blended learning in end of life care.

There will be three development groups:

a) Community group – to develop learning pathways for:

- out of hours GPs and DNs
- paramedics

b) Acute hospital group – to develop learning pathways for:

- doctors and nurses working with patients in last 48 hours of life
- other professionals working with patients in last 48 hours of life
- non-clinical staff who have contact with patients and/or families

c) Specialist palliative care group – to develop learning pathways for:

- inducting staff new to specialist palliative care services
- volunteers in specialist palliative care settings

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FI 1 – Extracts from the original service specification for RISE

Aims

- a) The provision of timely palliative intervention through a flexible, responsive service to support patients in crisis to remain at home
- b) The prevention of inappropriate emergency admissions to hospital for EOLC clients who have an acute crisis
- c) Facilitated discharge for EOLC clients admitted to the Acute Trust for whom speed of discharge is of the essence in order to meet preferred place of care
- d) Increase quality of care by offering people choice on where they would like to be cared for and/or die
- e) To increase death in preferred place of care to 80% of those with it documented by 2013
- f) Increase in the percentage of patients dying across home, care home and hospice settings, from current 42% to 70% where this is supported by patient choice by 2013
- g) Reduction from 58% to 30% of patients dying in acute hospital by 2013
- h) Benefits of change to impact on all patient groups including those with Long Term Conditions (LTC), cancer, dementia and frail elderly.

Expected Outcomes

The main objectives of the Rapid Response Service are that it should offer:

- Improved patient satisfaction
- An alternative to emergency admission to hospital
- Choice that allows more LTC patients to die at home
- A service that makes first contact within 20 minutes in times of crisis
- Patients the choice to be cared for and die in their preferred place of care
- Patients the opportunity to avoid the trauma of emergency admission to acute care
- For those patients who have been admitted to acute care, rapid discharge to die at home where that is their preference and the service can support their needs appropriately
- A flexible, timely response to unscheduled demand
- A service to patients with all conditions, with a particular requirement to address the needs of patients with non-cancer conditions including those with: Dementia Long term conditions in their last year of life Chronic Neurological conditions

Service Description

This service will respond to patients with a broad spectrum of need, including physical, psycho-social, spiritual and emotional. It will provide:

- Telephone advice and self-help referral where appropriate
- Access to equipment where necessary
- Health and social care assessment of urgently arising need,
- Short term planning to meet that need,
- The service will need to be able to offer appropriate intervention to meet identified need over a period of 6 days. This may include:
 - Symptom management
 - Facilitation of access to prescribing
 - Caring for urgent physical needs such as unblocking catheters
 - Basic nursing care at home
 - Social care support where appropriate
- Support which is able to meet those needs of carers related to the situation. The above to be provided by experienced and trained, qualified or unqualified staff as appropriate



- referral on and discharge to appropriate services within that time OR support of patient and family until time of death (whichever is shorter) ,
- comprehensive communication with GP and key worker during the period of intervention
- The service should be equipped to collect relevant data to be used to identify gaps in both their own service and the services provided by others in order that the patient pathway can be smoothed and improved.

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FI 2 – Care homes with nursing

Two full time practice educators offer intensive programmes of education to care homes involving them in the decision about what education provision they require to enable them to provide gold standard nursing care at the end of a resident's life.

A programme of education is then delivered to the home followed by long term support offered in the form of formal and informal drop in sessions where staff can raise education and EOLC management issues in confidence to the facilitators if required.

Two part time practice educators can offer homes six hours of education a year to those homes that feel they do not require such intensive support and education, if the educators feel that these homes require more intensive support they refer them to the full time educators.

Education Offered:

- Integrated Care Pathway for the Dying;
- Recognising Dying;
- Syringe Driver Training;
- Verification of Death;
- Communication skills for End of Life Care (Difficult Conversations);
- Symptom Control for Qualified Nurses;
- Symptom Control for Health Care Assistants;
- Spirituality;
- Loss and Grief;
- Bereavement Support Skills.

The use of the ICP is taught in all care homes together with a session on Recognising Dying, as effective use of the ICP requires knowledge and understanding of this process. 68% of homes regularly use the ICP documentation for End of Life Care Provision with many verbalising the benefits its contribution makes towards multi-disciplinary care, and how it helps the staff give effective care and comfort for their residents who are at the end of their lives.

Positive feedback has been received from GP's and CNS's about the confidence that staff in some of the homes have now gained around EOLC provision and about how accurately some staff now refer patient problems to them.

Feedback from GPs

"Thanks for your help. It has clearly made a huge difference! We now have very sensible discussions around EOLC. We are using the DNACPR forms and have had some very appropriate deaths without panic/ambulance/admission etc."

"The nurses at (care home named) are, at last, leading the discussion with relatives on this instead of defaulting to the GP (me!) every time."(GP)"

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Contributors

The following people gave up time to contribute to this work:

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Ali Flint	Specialist palliative care clinical nurse specialist
Nicky Peregrine	Specialist palliative care clinical nurse specialist
Geraldine O'Meara	Specialist palliative care clinical nurse specialist
Fi Elbourne	Specialist palliative care clinical nurse specialist
Kate Butcher	Practice development facilitator for EoLC
Claire Britton	Practice development facilitator for EoLC
Bernadette Ross	Director of nursing, Katharine House (independent hospice)
Neale Conner	Occupational therapist, specialist palliative care
Laura Carter	Commissioner NHS Oxfordshire PCT
Lucy Sutton	Associate Director for End of Life Care Programme and AQP Lead – NHS South Central



National End of Life Care Programme

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